Women's perspectives of radiotherapy combined with deep inferior epigastric perforator (DIEP) flap and transverse rectus abdominis musculocutaneous (TRAM) free flap breast reconstructions post mastectomy for breast cancer

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Abstract

Aim: To investigate women's perspectives of radiotherapy combined with deep inferior epigastric perforator (DIEP) flap and transverse rectus abdominis musculocutaneous (TRAM) free flap breast reconstructions post mastectomy for breast cancer.

Background: Breast cancer can be treated by a number of modalities. Two of these are surgery and radiotherapy. If a mastectomy is recommended an immediate breast reconstruction may also be offered. There are a number of different reconstructive techniques; one uses tissue from the abdomen, and another uses tissue and muscle. In some cases radiotherapy may be recommended and delivered post-operatively as an adjuvant. There is confusion in the literature whether radiotherapy has a detrimental effect on these autologous (tissue-only) reconstructions, and there is limited research in this arena from the patient's perspective.

Method: Three focus groups were held in London in 2013. The aim of these groups was to explore the experiences of women who had received this combination of treatment, and to identify their thoughts on whether post-operative radiotherapy impacted their tissue-only immediate breast reconstructions. Data from these focus groups were transcribed and analysed using framework analysis.

Results: Six themes emerged from the data; *Being changed, Control, Coping strategies, Information, Normalisation* and *Trust/faith in healthcare professionals.* The women did not appear to be worried about the combination of treatment or any effects the radiotherapy had on their immediate autologous breast reconstructions; furthermore, they would recommend this option to others in the same situation. The women discussed their experience of breast cancer and how this had affected them. The data illustrated that breast cancer and treatment reverberated through every aspect of the women's life; their self-identity, daily routines and experiences

with friends and family. In context of the enormity of the breast cancer experience, the combination of treatment with immediate autologous reconstruction followed by radiotherapy appeared well tolerated and not a notable issue for the participants. Although longer-term issues are not known, these women reported that other aspects of their treatment had been challenging, for example chemotherapy, but when reflecting on their whole experience these did not seem too great in hindsight.
Conclusions: This is the first study to report qualitative data on this specific combination of treatment. The findings of this research are that the participants did not voice concerns regarding the delivery of post-operative radiotherapy on their DIEP or TRAM flap immediate breast reconstructions. Understanding the thoughts and experiences of these women will furnish healthcare professionals with information, assist them when recommending treatment for women within this setting, and give confidence and encouragement when suggesting this combination of treatment. It is hoped that this will translate to a better patient experience and enable clinicians to target and assist with specific needs in a holistic manner.

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Glossary and definition of terms

Acute or immediate side effects – effects of treatment that occur within months

Adjuvant (treatment) – treatment delivered in addition to primary treatment

Autologous – tissue originating from the person's body

Benign – not cancer

Breast – either one of the two areas on the torso that house mammary glands

Breast cancer volume to host-breast-volume ratio – size of cancer in relation to the breast in which it is present

Breast implant – a prosthesis filled with silicone that is used to reconstruct the breast

Breast reconstruction – an operation to rebuild the breast mound after a mastectomy

Cancer /carcinoma – a disease in which cells divide abnormally and start to invade healthy tissue

Capsular contracture – when the area around the breast implant tightens up resulting in the implant becoming harder and the shape distorted

Chemotherapy – a systemic drug treatment for cancer

Deep inferior epigastric perforator (DIEP) breast reconstruction – a breast reconstruction that uses skin and fat from the abdomen to make a breast mound

Delayed breast reconstruction – a breast reconstruction performed as a separate operation at a later date after the mastectomy

Dry desquamation – scaling, flaking or peeling skin signalling the loss of some of the epidermal layer

Erythema – reddening of the skin accompanied with mild discomfort

Fat necrosis – when damaged tissue forms hard lumps

Fibrosis – benign connective tissue

Flap contracture – the shrinkage of a breast reconstruction donor tissue

Flap volume loss – a reduction in the amount of bulk of the donor tissue

Immediate breast reconstruction – a breast reconstruction that is performed at the same time as a mastectomy

In-situ breast cancer – breast cancer cells confined within the milk ducts or lobules of the breast

Intimacy – a private relationship that contains sexual activity or a closeness between people

Inframammary fold – where the lowest part of the breast meets the chest and trunk

Latissimus dorsi (LD) breast reconstruction – a breast reconstruction that uses muscle and skin from the back to make a breast mound

Long-term side effects – effects of treatment that occur after about a year

Mastectomy – surgical removal of the breast

Meta-synthesis – published literature that examines articles pertaining to a topic with the aim to interpret the findings of the collective group of research as a whole

Moist desquamation – loss of the skin's epidermal layer and exposure of the dermal layer, producing blisters or ulcers

Multi-focal – results from more than one focus

Oncological – treatment for cancer

Pathology – the detail and characteristics of tissue from under the microscope

Ptosis – drooping or falling of a part of the body, namely breasts or eyelids

Radiotherapy – a treatment for cancer that uses ionizing radiation

Re-operation – an additional surgical procedure required to complete the previous surgical procedure or any complications that may have resulted from it

Transverse rectus abdominis musculocutaneous (TRAM) breast reconstruction – a breast reconstruction that uses muscle, skin and fat from the abdomen to make a breast mound

Chapter 1: Introduction to the study

1.1 Background

This study is about the experience of women who have undergone post-operative radiotherapy combined with deep inferior epigastric perforator (DIEP) flap or transverse rectus abdominis musculocutaneous (TRAM) free flap immediate breast reconstructions following a mastectomy for breast cancer. The study explores the women's perspectives of this combination of treatment to create a picture of what the experience means to them. It is hoped this evidence of actual experience will inform both healthcare professionals recommending treatment plans and the women who are considering them.

Breast cancer is a significant health concern across the world, with almost 1.7 million new cases a year, and the highest incidence is found in developed countries (IARC 2014). Advances in modern healthcare in such countries have seen the development of many more refinements in the surgical and medical management of the disease.

When a mastectomy is recommended, as long as there are no other significant health or treatment issues, the National Institute of Health and Clinical Excellence Guidelines (NICE 2009) are that an immediate breast reconstruction should also be offered. There are various techniques of reconstruction. The DIEP flap uses skin, fat and blood vessels from the abdomen while the TRAM free flap breast reconstruction uses muscle in addition to skin, fat and blood vessels from this area in order to create a breast mound. This extensive surgery can take up to twelve hours and requires substantial recovery time for the patient. Sometimes radiotherapy is recommended after surgery as part of the oncology treatment, and a possible treatment effect of this can be shrinkage in or lumps developing in the reconstructed breast.

1.2 The researcher

As a clinical nurse specialist (CNS) in a major cancer centre in the UK, I have been involved in the care of women having post-operative radiotherapy after DIEP flap and TRAM free flap breast reconstructions following a mastectomy and developed an interest in the experience of these women following this procedure. This is especially the case as some clinicians and breast units do not offer this combination of treatment due to their perceptions of adverse treatment effects. Some women may therefore only be offered a delayed breast reconstruction, a temporary one which would need to be refashioned after time, or possibly radiotherapy prior to surgery.

1.3 The need to understand the patient's perspective

The literature is contradictory and confusing in places, and little of it is from the patient's perspective. This means there is a variation in clinical practice that is based on shaky foundations. What literature there is concentrates mainly on the clinician's view point, and whilst this is important, it is crucial to know what the patients who have the experience think and feel regarding this combination of treatment. They are the ones who have to live through the treatment and with any resulting consequences. To this end, I decided to use focus groups to explore whether these women thought there was an issue receiving radiotherapy post DIEP or TRAM free flap immediate breast reconstructions.

1.4 Signposting of this thesis

Chapter two will describe the background to breast cancer, some treatment modalities and nursing implications of these.

Chapter three will be a gap analysis review of the literature on the effects of post-operative radiotherapy on TRAM and DIEP flap immediate breast reconstructions, dividing the literature into themes of long-term side effects, cosmetic outcome, acute/immediate side effects, co-variables and re-operation rates. This chapter will summarise what is known in relation to

post-operative radiotherapy on TRAM and DIEP flap immediate breast reconstructions. Understanding what evidence there is allows the correct questions to be posed to this group of women.

Chapter four is dedicated to methods and methodology, and will discuss research paradigms. . It will then describe practicalities of the focus groups; sample selection, recruitment, venue, ethical considerations, analytical process using Framework Method, justifying my use of it, as well as measure to ensure trustworthiness in the study.

Chapter five presents the findings of the study using the six identified themes.

Chapter six discusses the findings in relation to what is known on the subject and what this research has added. This will be within the background of appropriate published literature. The chapter will also describe strengths and limitations of this work in addition to implications for practice and future research.

Chapter seven will provide a summary of the thesis in addition to a conclusion and a section on what the future may bring to this group of patients.

Chapter 2: Breast cancer

2.1 Introduction

This chapter provides a summary of the significance of breast cancer and current ways to treat the disease relevant to the aims of this study.

2.2 Breast cancer

Breast cancer is the most common cancer in the United Kingdom (UK), with approximately 49,936 women with a new diagnosis in 2011, and an estimated lifetime risk quoted as one in eight (Cancer Research UK 2014). The five-year relative survival rate for women with breast cancer is increasing and is currently estimated at 85% in England (Office for National Statistics 2012).

Breast cancer is a disease that affects men as well as women. Of the 50,285 new diagnoses of breast cancer made in the UK in 2011, over 99 per cent are women (Cancer Research UK 2014). Although it is important to recognise that men are also affected by breast cancer, for the purposes of this study considering breast reconstruction, the information relating to breast cancer and its management will only relate to women with breast cancer.

2.3 Surgery for breast cancer

There are primarily five treatment modalities for breast cancer: surgery, chemotherapy, radiotherapy, hormone therapy and biological therapy. Surgery is often the first treatment carried out. Clinical and pathological features of the breast cancer, along with patient characteristics, influence the type of surgery recommended to the individual woman. These include the breast cancer volume to host-breast-volume ratio (size of cancer in relation to the breast in which it is present), if the disease is multi-focal, and the presence or absence of extensive in situ disease (Harmer 2011). Approximately 33% of all women diagnosed with symptomatic breast cancer

will have disease that is unsuitable for breast conserving surgery and will be advised to have a mastectomy (Dixon & Thomas 2012).

2.3.1 Breast reconstruction

A breast reconstruction is an operation to recreate a breast mound in order to correspond to the remaining breast and regain symmetry following a mastectomy (Jeevan *et al*. 2011). This operation can be performed at the time of the mastectomy: an immediate reconstruction, or at a later date: a delayed reconstruction. Breast reconstruction is accepted as a safe option for the majority of people undergoing a mastectomy (Malata *et al*. 2000). In 2002, NICE stated breast reconstruction should be offered to all women with breast cancer at the time of mastectomy (NICE 2002). This guidance was amended in 2009, when it advised that reconstruction should be offered to those facing mastectomy with a caveat for those with significant co-morbidities or those requiring adjuvant treatment (treatment recommended in addition to surgery such as post-operative radiotherapy or chemotherapy) that might preclude this option (NICE 2009). Currently, in England and Wales, about 21% of women undergo an immediate breast reconstruction (Jeevan *et al*. 2011), with most doing so to restore body image and feelings of womanliness, and in order to be able to dress as they wish (Reaby 1998, Duggal *et al*. 2013).

2.3.1.1 Timing of breast reconstruction

There are advantages and disadvantages to immediate and delayed breast reconstruction surgery. Having a reconstruction at the time of mastectomy results in only one main operation and one period of hospitalisation, and also allows for preservation of the inframammary fold and use of the breast skin, which leads to better cosmetic outcome (Thiruchelvam *et al.* 2013). The disadvantages of immediate reconstructions include a limited period of time for patient decision making to take place, longer initial operation times and possible delays in delivery of oncological treatments if post-operative complications occur (Weiler-Mithoff 2009).

Delayed breast reconstructions are performed post oncology treatment, and do not potentially delay vital treatment. They also allow the patient more time for decision making. Disadvantages of this technique include two main surgical procedures and hospitalisations, the psychological effects of living without a breast for some time, increased costs, the need to replace and transport a larger amount of breast skin, and having to work with the initial mastectomy flaps which may be thin or scarred, particularly following radiotherapy (Weiler-Mithoff 2009).

2.3.1.2 Breast reconstructive techniques

There are different techniques of breast reconstruction, using tissue expanders, implants and the patient's own tissue (autologous tissue flaps). Sometimes a combination of implants and tissue is used. The most straightforward reconstruction is the tissue-expander reconstruction. For this, a silicone implant is placed in a purpose-made submuscular pocket in the anterior chest wall. This specially designed implant contains an empty chamber with a tube attached to it in order to allow saline to be injected post-operatively repeatedly until the desired size is achieved. This in turn stretches the skin and forms a breast mound (Weiler-Mithoff 2009). When the desired shape has been achieved, the tissue expander can be replaced at a second operation with a fixed volume silicone implant. This reconstructive technique is most useful for women with small breasts with no ptosis (natural droop) (West 2011).

Breast reconstruction using autologous tissue involves using the patient's own muscle and subcutaneous tissue, together with a flap of skin from a donor site, and transferring it to the breast site. The use of a flap requires a lengthier, more complicated surgical operation, resulting in a superior cosmetic outcome and ptosis unachievable when using an implant-only technique (Colen & Karp 1999). These operations can take anything up to twelve hours to complete. The tissue is either removed from the latissimus dorsi (LD) muscle on the back or the lower abdominal wall. If the LD is used, the muscle is freed up with its skin and blood supply, rotated through the

axilla and placed on the chest wall as a reconstructed breast (West 2011). The LD is limited in volume and is usually used in partnership with a silicone implant.

The TRAM reconstruction was first described by Hartrampf in 1982 and uses the muscle, skin and fat from the abdominal area; it is similar to performing an abdominoplasty (Kanchwala & Bucky 2008). There are two types of TRAM reconstructions. A pedicled TRAM flap technique is when an island of tissue is raised with its blood supply and rotated onto the chest wall where it is used to create a breast shape. A free TRAM flap entails tissue and muscle being completely cut from the abdomen with its own blood supply, and then re-plumbed to blood vessels using microsurgery.

The DIEP is the most recent development in breast reconstruction. It utilises abdominal fat and tissue without the use of muscle, reducing the likelihood of hernias. Once again, microvascular surgery is required to connect blood vessels to the internal mammary artery (West 2011), as shown in Figure 2.1.

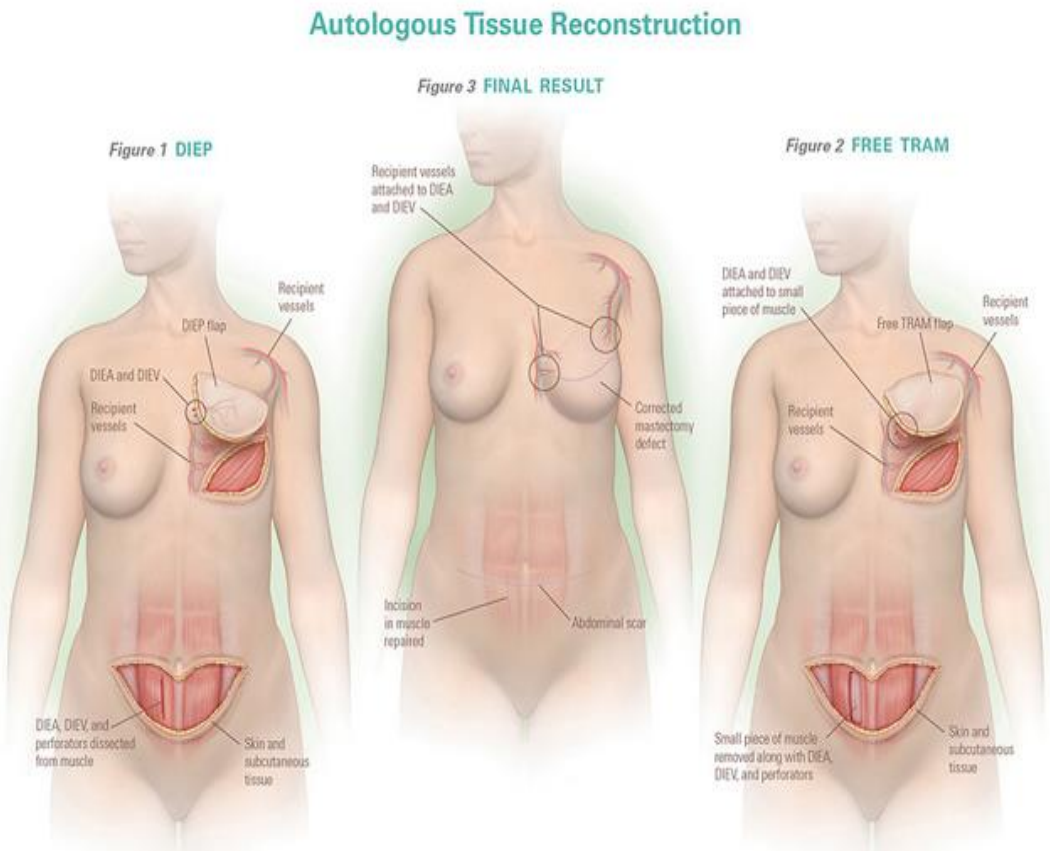
TRAM and DIEP flap tissue reconstructions have become the 'gold standard' of breast reconstructions in terms of cosmetic outcome (Kanchwala & Bucky 2008) and, because they contain fat, when a woman's weight changes, so does the reconstructed breast (Vasconez *et al*. 1991). They are a particularly good choice for the larger-breasted woman with ptotic (drooping or sagging) breasts (West 2011).

2.3.1.3 The national mastectomy and reconstruction audit

The NHS Information Centre for health and social care has published reports that relate to the National Mastectomy and Reconstruction Audit. The aim of this audit was to scope the provision of mastectomy and reconstruction services within England in addition to uncovering outcomes of care for women who have a mastectomy with or without a reconstruction. This audit has ascertained baselines in relation to patient satisfaction and quality of life outcomes after mastectomy and breast reconstruction. In addition to other

findings, the fourth report of this audit details encouraging data from a patient's perspective regarding their satisfaction with their clinical team (85% of women reported being very satisfied), and regarding their satisfaction in their involvement surrounding decision making (81% of women who had an immediate breast reconstruction reported being very satisfied, 87% of those post delayed reconstruction and 75% of those who had a mastectomy with no reconstruction). Data is also supplied regarding the women's satisfaction relating to the appearance of their reconstructed breast in addition to their physical, sexual and emotional wellbeing 18 months after surgery. Perhaps not surprisingly, the reported levels of emotional and sexual wellbeing from the sample (n=8,536) at this time point revealed that those who had a mastectomy felt less confident, less sexually attractive and less satisfied with how they looked in the mirror clothed when compared to those who had had a breast reconstruction. What is interesting is that those who had a delayed breast reconstruction felt more confident (92% compared to 85%), more sexually attractive (68% compared to 57%) and more satisfied with how they looked in the mirror clothed (93% compared to 90%) at this time point when compared to those who had undergone an immediate breast reconstruction (The NHS Information Centre 2011). This audit does not detail if any of these women had received adjuvant radiotherapy, or if there was any differences in satisfaction between those who had and those who had not undergone this combination of treatment.

Figure 2.1 Autologous tissue breast reconstruction



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2.4 Radiotherapy

Radiotherapy is a crucial component for many patients treatment for breast cancer. It is the use of ionising radiation to destroy tumour cells (Burnet 2011), and is undoubtedly a positive intervention (Glover & Harmer 2014). Radiotherapy can be given to those with early stage breast cancer as an adjuvant treatment after breast-conserving surgery, and this package has equal outcomes to mastectomy (Fisher *et al*. 2002). Radiotherapy can also be delivered post mastectomy to improve local and regional control of breast cancer and reduce death from the disease. Current recommendations for post mastectomy radiotherapy include cases where the cancer is large (T3/T4 tumours), where there are positive surgical margins or the cancer was close to the chest wall or where lymph nodes contain metastatic spread (Gebski *et al*. 2006) NICE (2009) suggest post mastectomy radiotherapy

should be offered to patients who are at a high-risk of developing a local recurrence. The Early Breast Cancer Trialists' Collaborative Group (2014) undertook a meta-analysis of randomised controlled trials that related to radiotherapy being delivered after a mastectomy. They concluded that for 1,314 women who had between one to three positive lymph nodes, radiotherapy reduced death from breast cancer by a fifth (RR 0·80, 95% CI 0·67-0·95, 2p=0·01), and both locoregional recurrence (2p<0·00001), and overall recurrence (RR 0·68, 95% CI 0·57-0·82, 2p=0·00006).

As the primary mode of action in radiotherapy treatment is the killing of cells to prevent replication, other non-cancerous cells may be affected. Side effects of radiotherapy can be split into immediate/early and late. Immediate effects of radiotherapy to the breast or chest wall include local reactions such as erythema (reddening), itching, dry desquamation (scaling, flaking or peeling), and moist desquamation (exposure of the epidermal layer producing blisters) of the skin (Burnet 2011). Up to 85% of patients will experience some form of skin reaction (Glover & Harmer 2014).

Late side effects of radiotherapy to the chest wall can include thickening of the local skin, fibrosis and hyperpigmentation. There is also a chance that some lung tissue may inadvertently be damaged, which could result in a cough, fibrosis of the lung or a thickening of the pleura. Similarly cardiac damage has been identified as a possible late effect of radiotherapy when delivered to the left side, and each clinician will individualise treatment in an attempt to minimise cardiac toxicity (Burnet 2011). In addition to these potential treatment effects, and although uncommon, radiotherapy to the breast or chest wall is related to a significant increase (p 0.02) in the number of radiation-induced sarcomas and lung cancers at 10 years when compared to those who have not received radiotherapy (Kirova *et al.* 2007, Taghian *et al.* 1991).

2.4.1 Radiotherapy post breast reconstruction

Like all treatments, radiotherapy has side effects and there is much debate about the compatibility of breast radiotherapy after breast reconstruction. From an oncological safety point of view, the breast reconstruction will alter the profile of the chest wall that in turn may reduce the amount of radiation delivered to the area. Some suggest that to combat this a wider radiation field is deemed necessary (Buchholz *et al.* 2002, Schechter *et al.* 2005, Motwani *et al.* 2006). Although some patients will need radiotherapy post mastectomy, there is an inability to confidently determine pre-operatively which patients will require this treatment, and decisions about reconstructions and radiotherapy are complex (Kronowitz & Robb 2004). There is evidence that radiotherapy has a detrimental effect on implant-based reconstructions in terms of cosmetic outcome and complication rate, especially relating to capsular contracture, when the pocket around the implant tightens, resulting in the implant becoming harder and the breast shape distorted. This is three times more likely to occur if radiotherapy is delivered post implant reconstruction (Behranwala *et al*. 2006).

Although there is literature illustrating the negative effect of radiotherapy on implant-only breast reconstructions, little has been known about effects it has on the tissue-only technique (Tran *et al*. 2000, Tran *et al*. 2001) and even less on what the patient's perspective on this is. Confusion in the literature is apparent as to whether this order and combination of treatment gives rise to potential problems, such as flap contracture, fat necrosis, the need for revision surgery or a reduction of the cosmetic outcome.

Schaverien *et al.* (2013) published a systematic review of published literature that relates to outcomes of postoperative radiotherapy after immediate autologous breast reconstruction. This quantitative review is detailed further in the discussion chapter (6.3), however the authors concluded that there are similar complication rates for patients who had immediate autologous reconstructions and post-operative radiotherapy when compared to those who did not receive radiotherapy and that as a number of studies reported

satisfactory outcomes for those who had received radiotherapy, that this combination of treatment should be considered by healthcare professionals.

2.5 Nursing implications

In the United Kingdom, the CNS in breast care is responsible for providing information and support to patients throughout their breast cancer trajectory (Royal College of Nursing 2007). This encompasses assisting with decision making about treatment. Whether or not to have an immediate breast reconstruction is generally a decision for the patient, and there can be much discussion of the pros and cons. It is important to have a detailed knowledge of breast reconstruction, effects of radiotherapy and of the patient's perspective. No matter what clinicians may consider the effects of these treatments are, the focus needs to be what the patient experiences and feels the impact is, and the consequences of this combination of treatment.

2.6 Summary of chapter

This chapter has introduced breast cancer and given some background to selected treatments used. It described breast reconstruction and timing, along with some of the techniques offered to women. The importance of understanding the consequences of treatment from a patient's perspective has also been underlined.

Chapter 3: Gap analysis: a scoping review

3.1 Introduction

This chapter contains a scoping review of the literature conducted prior to undertaking the study regarding post-operative radiotherapy on DIEP and TRAM free flap immediate breast reconstructions. The purpose of this was to provide background information and to understand what was known on this topic, thereby identifying gaps and producing the most useful question to ask for this research. This process can also be called a gap analysis. This literature will be split into themes of long-term side effects, cosmetic outcome, acute/immediate side effects, co-variables and re-operation rates.

3.2 Scoping review

Arksey and O'Malley (2005) describe scoping studies as a type of literature review, useful for identifying and mapping knowledge within an area of interest.

A scoping review and gap analysis was undertaken in order to identify the extent and type of available literature pertaining to the effects of radiotherapy on the TRAM/DIEP technique of breast reconstruction when it is performed at the same time as the mastectomy for the treatment of breast cancer, including the patient perspective. This was deemed preferable to a systematic review, as it would encompass a broader perspective of the topic. The knowledge generated from the scoping review informs this study, as it illustrates what evidence was available and what was known or not known on this subject. The aim was to identify any deficit (gap) in knowledge that would act as the arena for this study and therefore define the questions that needed to be answered. Typically a scoping review provides a relatively uncritical mapping of the literature on a topic rather than a critical analysis of the quality of the evidence as would be presented in a systematic review (Rumrill *et al*. 2010, Grant & Booth 2009, Brien *et al*. 2010).

3.3 Aims

The aims of this scoping review are to:

- Collect and collate the literature and information associated with the effects of radiotherapy on autologous 'tissue-only' immediate breast reconstructions.
- Chart and evaluate what is known on this subject.
- Determine patient's viewpoint and perspectives of this treatment.

3.4 Search strategy

The scoping review used the methodological framework described by Arksey and O'Malley (2005). This five-stage process begins with identifying the research question; deciding the subject of interest for the study. Stage two involves identifying relevant studies. Stage three is study selection, essentially sifting through the studies ensuring each one included is relevant before the data is charted, which becomes Stage four. Stage five of the process is assembling the findings.

3.4.1 Electronic database searching

An advanced search was conducted using Medline and CINAHL. NHS Evidence was used to allow a mixture of evidence-based and grey literature. Prior to the search, there was a discussion with one of the medical school librarians to confirm that the proposed search terms were appropriate and would identify relevant articles, and to minimise selection bias.

The search terms used focused on the concept and terminology. The terms 'breast' and 'reconstruction' were used as well as 'breast reconstruction', in order to capture studies using the phrase. To be as inclusive as possible, the section marked 'map to thesaurus' was ticked. This looks at the underlying thesaurus structure and subject headings that the database uses. 'Mammaplasty' was listed and, although not currently a term used in the UK for this surgery, it was deemed important to include this term as it may be used in North American literature. 'Implantation' was also listed as an additional term, thus the Explode button was used to broaden the search to

include both these terms. The grouped terms ‘breast’ and ‘reconstruction’, ‘mammoplasty’, and ‘implantation’ were used to get the first concept (n=8,473 articles in Medline, n=301 articles in CINAHL).

The second concept in the scoping review was ‘radiotherapy’. Again the thesaurus within the database was used as radiotherapy is mainly a UK term. Radiation therapy is the term used in North America for this treatment, it was important the search was inclusive of this term, as well as, the other suggestions; exemplar ‘adjuvant radiotherapy’. ‘Radiotherapy’ was grouped in all of its forms to get the second concept (n=205,663 articles in Medline, n=12,698 articles in CINAHL).

The two concepts were linked in a search to retrieve papers concerned with both breast reconstruction and radiotherapy (n=671 articles in Medline, n=48 articles in CINAHL). The timing issue was then addressed. Reconstruction can be performed at the time of the mastectomy or as a delayed procedure. In order to identify the effects radiotherapy has on a breast reconstruction, the operation would have to be done at the time of the mastectomy, the terms ‘immediate’, ‘surgical timing’, ‘immedia*’, ‘time factors’ and ‘treatment outcome’ (as suggested by thesaurus) were used (n=1,699,267 in Medline, n=81,076 CINAHL).

These terms were then grouped with the previous search to give 429 possible articles in Medline and 19 from CINAHL, which detailed information on the effects of radiotherapy on breast reconstruction. Once the retrieved evidence pertaining to this subject had been reviewed, a subset search presented the articles in the context of the patient perspective. ‘Patient perspective’ was added as a search term, including all attitudes to health and satisfaction (n=261,493 articles in Medline, n=60,022 articles in CINAHL). All concepts were then linked giving 91 articles from Medline and 8 from CINAHL. Table 3.1 illustrates the terms used and number of articles identified during the search process using Medline.

Table 3.1 Search strategy and numbers of articles identified in Medline

	MEDLINE Search History	Number of articles
1.	'breast reconstruction' (title/abstract)	3824
2.	(explode) Mammaplasty	7256
3.	Radiotherapy (title/abstract)	100822
4.	(radiation AND therapy) (title/abstract)	63066
5.	'radiation therapy' (title/abstract)	45461
6.	'radiation oncology' (title/abstract)	2847
7.	(explode) Radiotherapy/ OR (explode) Radiotherapy, Adjunct/ OR (explode) Radiotherapy ,Computer-assisted/ OR (explode) Radiotherapy , Conformal/ OR (explode) Radiotherapy Dosage/ OR (explode) Radiotherapy , High-energy/ OR (explode) Radiotherapy , Intensity-modulated/ OR (explode) Radiotherapy Planning, Computer-assisted	126722
8.	1 OR 2	8473
9.	3 OR 5 OR 7	205663
10.	8 AND 9	671
11.	immedia* (title/abstract)	271306
12.	Timing (title/abstract)	70762
13.	'surgical timing' (title/abstract)	224
14.	(explode) Time factors / OR exp Treatment outcomes	1424845
15.	11 OR 12 OR 13 OR 14	1699267
16.	10 AND 15	429
18.	(patients AND perspective) (title/abstract)	22270
19.	'patients perspective' (title/abstract)	2107
20.	(explode) Attitude to health	260380
21.	(explode) Patient satisfaction	53119
22.	19 OR 20 OR 21	261493
23.	10 AND 22	91
24.	18 OR 20 OR 21	279627
25.	10 AND 24	93
26.	16 OR 25	452
27.	26 NOT 16	23

3.4.2 Hand-searching

Hand searching of journals was not undertaken during the scoping study. Senior medical colleagues were approached to identify any specific journal that could be considered beneficial to hand-search. It was generally agreed

that there was no rationale for selecting any one journal so this type of hand searching did not take place. The reference lists of the articles collected were reviewed in order to identify additional relevant papers.

3.5 Study selection, inclusion/exclusion

The studies retrieved from the electronic search spanned over 20 years. It was important to review all the literature relating to immediate breast reconstruction and radiotherapy, so abstracts of the 448 (429 Medline and 19 CINAHL) studies were read and a decision was made as to their relevance. The subset of 96 (91 Medline and 5 CINAHL) articles relevant to radiotherapy and breast reconstruction effects was then evaluated for content. Studies in languages other than English were excluded due to the lack of resource for translation. Twenty-four studies were removed: ten in French, three in German and three in Hungarian, two in Chinese, and one each in Japanese, Czech, Polish, Serbian, Spanish and Italian. There does not appear to be any seminal work or substantive timelines that relate to this arena and so the time frame of papers was not restricted. All other papers were inspected for suitability for inclusion.

The reference lists of each paper were checked and an additional three papers were identified that related directly to the subject, thus they were included in the scoping exercise. Three papers discussed the oncological safety and efficiency of radiotherapy after breast reconstruction; these were removed, along with three papers that referred to performing a breast reconstruction after radiotherapy. The papers were sifted to ensure only those relating to the effects of radiotherapy on breast reconstruction were pooled. The last step was to distil the type of breast reconstruction the papers were concerned with. Those relating to TRAM/DIEP studies were colour-coded red; the most relevant studies. Those papers that related both to TRAM/DIEP and silicone implant reconstructions were included, but colour-coded black; only the relevant parts of these papers would be charted. Papers that were not empirical studies, but more discursive pieces and expert opinion, were colour-coded green. Any papers that only related to

implant reconstruction were excluded. By the end of this process there were 20 ‘red’ studies and 18 ‘black’ mixed ones for charting, with 31 ‘green’ background papers (Figure 3.1). The majority of articles were accessed through the medical school library; five were obtained via the British Library.

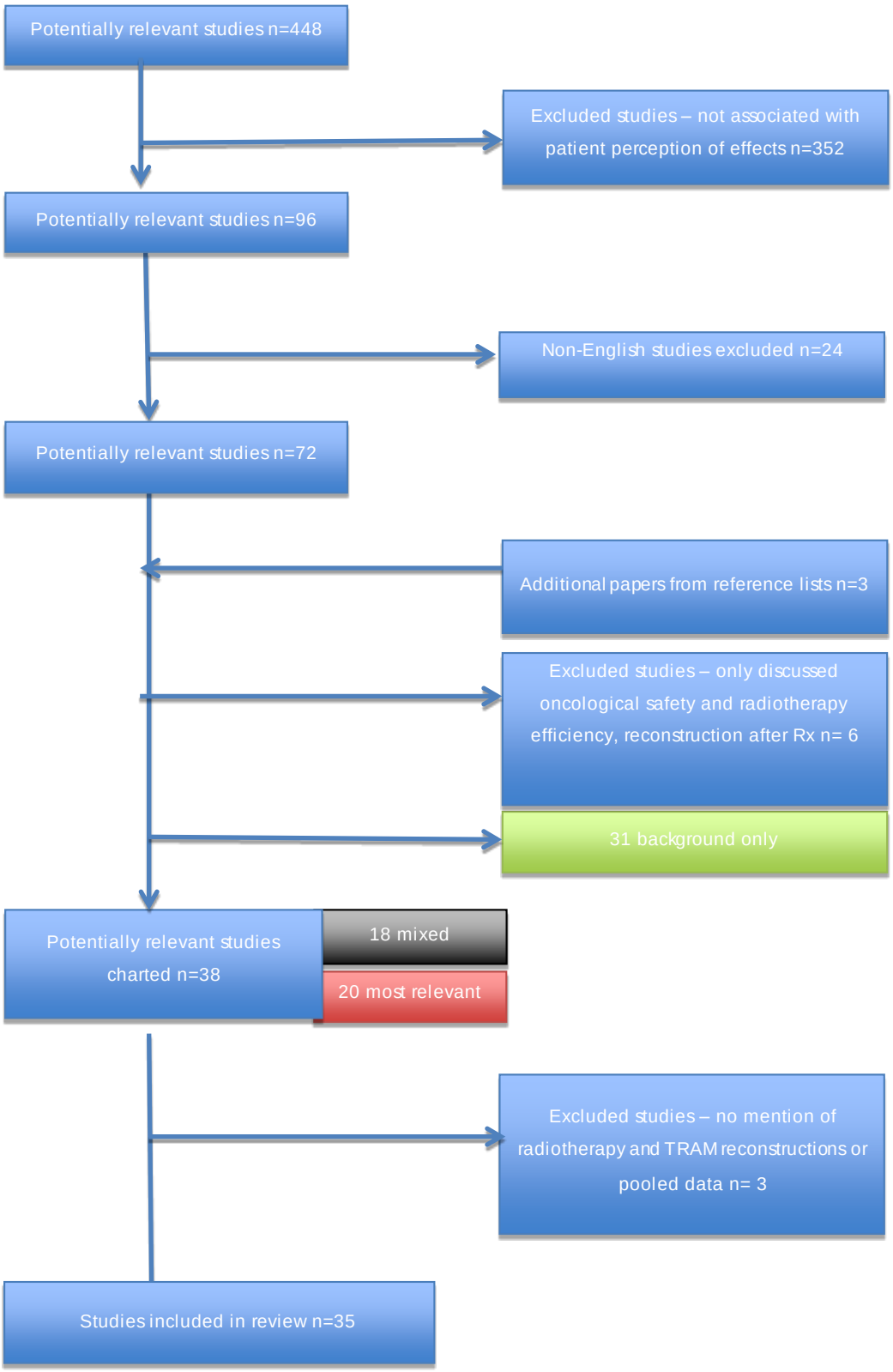
3.6 Charting

The information from 38 research studies was charted in a matrix, 35 of these met the search criteria and were deemed worthy of inclusion in the final review. Articles were placed under headings detailing the research question, research design, outcome measures, results and comments. The ‘red’ articles were input first in alphabetical order (Appendix 1), then the ‘black’ articles (Appendix 2). Lastly the ‘green’ articles were read as background reading and expert opinion. Figure 3.1 gives a flow diagram of the review process.

3.7 Overview of the studies

The included literature was published between 1991 and 2011, and originated from nine countries. Twenty-five papers were from North America, three from the United Kingdom and two from China. Australia, Thailand, Singapore and Israel contributed one paper. A further study was jointly written by clinicians from Croatia and Austria. The majority (n=32) were single centre studies, and there were three multi-centre studies; two were two-centre studies, the other a 12-centre study. Thirty-one of the studies were retrospective and four prospective. The studies had sample sizes ranging from 10 to 919 participants.

Figure 3.1 Flow diagram of scoping review process



3.8 Overview of the findings

The first aim of the review was to identify the effects of radiotherapy on autologous 'tissue-only' immediate breast reconstructions post mastectomy. Of the 35 studies, 11 concluded radiotherapy does have an adverse effect on immediate breast reconstructions and 20 concluded that it has no effect. The remaining four studies detailed a proviso in their conclusions; two studies stated if radiotherapy is to be delivered post-operatively to a breast reconstruction, a tissue-only technique should be used. The other two studies stated radiotherapy can be successful, but only in certain cases if specific risk factors are not present, and that the timing and technique of reconstruction should be carefully considered pre-operatively. The remaining studies reviewed other issues related to patient satisfaction and cosmetic results. The literature on the whole was difficult to unpick and many papers used pooled data on the different types of breast reconstruction. However, it was possible to identify recurring themes.

3.8.1 Themes

Five themes were identified within the literature from all of the papers of all designs:

- the long-term complications of the reconstruction post radiotherapy
- cosmetic outcome
- acute/immediate complications
- whether co-variables, for example smoking or obesity, contribute to the effect radiotherapy has on immediate breast reconstructions
- re-operation rates

These themes will be discussed individually detailing particular research and are listed against the relevant papers in Table 3.2.

Table 3.2 Matrix of identified themes

Author	Long-term side effects	Cosmetic outcome		Acute/ immediate side effects	Co-variables	Re-operation rates
		Patient	Physician			
Adesiyun *et al.* (2011)	✓	✓				
Albino *et al.* (2010)	✓				✓	✓
Alderman *et al.* (2002)	✓				✓	
Anderson *et al.* (2004)	✓		✓			
Berry *et al.* (2010)					✓	
Carlson *et al.* (2008)	✓					
Chatterjee *et al.* (2009)	✓					
Chawla *et al.* (2002)	✓		✓		✓	
Foster *et al.* (2005)	✓					
Halyard *et al.* (2004)	✓	✓		✓		
Hanks *et al.* (2000)				✓	✓	
Huang *et al.* (2006)	✓	✓		✓		
Hunt *et al.* (1997)	✓	✓				
Jhaveri *et al.* (2008)	✓	✓				
Lee *et al.* (2010)	✓	✓		✓		
Losken *et al.* (2004)						✓
Makmur *et al.* (2003)	✓				✓	
Mehta & Goffinet (2004)		✓	✓	✓		
Moscona *et al.* (2006)		✓				
Mosahebi *et al.* (2007)		✓	✓			
Proulx *et al.* (2002)		✓	✓			
Rogers & Allen (2002)	✓		✓		✓	
Roje *et al.* (2010)		✓			✓	
Rusby *et al.* (2010)						✓
Shaikh-Naidu *et al.* (2004)		✓				
Sitathanee *et al.* (2005)				✓		
Soong *et al.* (2004)	✓	✓		✓		
Spear *et al.* (2005)	✓		✓			
Tran *et al.* (2000)	✓					
Tran *et al.* (2001)	✓			✓		
Tran *et al.* (2011)	✓					
Watterson *et al.* (1995)	✓				✓	✓
Williams *et al.* (1997)	✓					
Wong *et al.* (2008)			✓			✓
Zimmerman *et al.* (1998)	✓	✓				
Total	**23**	**19**		**8**	**9**	**5**

3.8.1.1 Long-term side effects

Long-term side effects included fibrosis, fat necrosis, flap volume loss and flap contracture. Twenty-three papers discuss this theme, 15 of these are purely within the arena of tissue-only breast reconstructions, and eight of these investigate the long-term side effects for people with all types of breast reconstructions.

Chawla *et al*. (2002) measured the complication rate of 48 patients; 30 had a TRAM reconstruction (16 of these experienced post-operative radiotherapy) and 18 had implant-only reconstruction (with 14 of these experiencing radiotherapy). This study suggests a complication rate of 12% for those post TRAM reconstruction and 53% for those post implant reconstruction, and concluded that TRAM reconstruction technique has lower complication rates. However, data in this study are pooled and, while it is possible to establish how many patients experienced radiotherapy, it cannot be determined which reconstruction they had, or if this resulted in more complications. The paper does state the sequence of radiotherapy and reconstruction is not statistically significant in relation to rate of complications. Alderman *et al*. (2002) similarly concluded that radiotherapy does not have any effect on total complication rate, although in this study, the authors declare that reconstruction type does not have any effect on this rate either. They did, however, find that the timing of reconstruction is related to complications experienced and that complication rates were significantly higher for those who have their reconstructions performed immediately at the time of the mastectomy. This study once more grouped the patient variable of radiotherapy, making it is difficult to interpret which women with which reconstruction technique experienced radiotherapy post-operatively, and how many complications these women encountered.

The Anderson *et al.* (2004) paper considered the three-year actuarial complication rates between implant-only and tissue-only reconstructions, and reported no difference between these. Furthermore, the authors concluded there was no difference in complication rate for women who experienced radiotherapy pre- or post-operatively. Once more it is not easy to unpick the

data and identify which women received radiotherapy and when this was in relation to their reconstruction surgery.

All the patients in the sample (n=25) in the Soong *et al.* (2004) study received radiotherapy, and no flap loss or fat necrosis resulted. They concluded that women who have tissue-only reconstructions tolerated this treatment well and did not experience an increased incidence of complications. Similarly, all of the women (n=92) in the research conducted by Jhaveri *et al*. (2008) received radiotherapy, although there was a mixture of tissue-only and implant-only breast reconstruction techniques. The patients who had tissue-only reconstructions had no severe complications and only 9% experienced poor functional results, compared to 33% and 55% for those post implant reconstruction. The authors concluded that women in their study with implant reconstructions experienced more long-term complications than those with tissue-only reconstructions, and that radiotherapy was well tolerated for the latter technique.

Tran *et al.* (2011) reviewed the medical records of all their patients who had a breast reconstruction within a five-year period. Fifty-one (29%) of their sample (n=175) experienced radiotherapy on tissue-only reconstructions. No statistical difference in overall complication rates in the group who received radiotherapy versus the non-irradiated group was illustrated. However, the independent effects of tissue-only and implant reconstructions cannot be determined, as the complication rates for all types of reconstruction are reported together.

Lee *et al*. (2010) concluded that radiotherapy post reconstruction increased overall complication rates. Fifty-nine people were in this arm of their study, and these were a mix of implant and tissue-only reconstructions. The tissue-only group also contained people who had LD reconstructions. The tissue-only group had the highest incidence of long-term complications (33.9%) and this was statistically significant when compared to those who did not require radiotherapy. The paper concluded that there were comparable rates of fat necrosis for the tissue-only group and for those who did not receive

radiotherapy. Similarly, Adesiyun *et al*. (2011) reported a significantly increased risk of complications from those who received radiotherapy on all types of reconstruction, 23 (20%) of 113 women had radiotherapy post TRAM reconstruction, and six of these experienced late complications (29%). There were, however, too few patients within each type of reconstruction group to have statistical power.

Of the 15 studies with a focus purely on the effect of radiotherapy on DIEP and TRAM flap reconstructions, the majority (nine) concluded there was no increase in long-term complication rate post radiotherapy. Makmur *et al.* (2003) did not find any difference in rates of fat necrosis or fibrosis in their study, although it is not clear if this was assessed through reading medical notes or from a clinical examination. Additionally their sample size is small; it consisted of 46 DIEP reconstructions. Although 11 were recommended post-operative radiotherapy, some were still undergoing this and only two were a year post completion of this treatment.

There was no flap loss detected in the Huang *et al*. (2006) research, although they did report an 8.5% increase in fat necrosis for those post radiotherapy (seven patients out of 82). Zimmerman *et al.* (1998) suggested radiotherapy post TRAM reconstruction appears safe; they did not experience any flap complications or losses. Hunt *et al.* (1997) agree with this conclusion as their study did not experience any flap loss, although they did document two incidents of fat necrosis. Spear *et al.* (2005) compared two groups; those who experienced radiotherapy post TRAM flap against those who did not require radiotherapy post TRAM flap. Their results stated there is no statistical significance between these two groups with reference to complete or partial flap necrosis.

Foster *et al.* (2005) had a sample of 252 patients, although only 35 had radiotherapy. This study reported fat necrosis in three patients (9%) who experienced radiotherapy, and volume loss was identified in two patients (6%). The authors concluded that immediate TRAM reconstructions should be considered regardless of the need for post-operative radiotherapy.

Through the use of a validated mammometer (Perspex cylinder with a piston), Chatterjee *et al*. (2009) investigated volume change of DIEP flap reconstructions. In an attempt to blind the assessors, patients who had not received radiotherapy had black dots drawn on the breast area to match the radiotherapy tattoos of the sample that had experienced this treatment. The authors reported no statistical significance post radiotherapy when compared to the non-radiotherapy group.

Two papers stated there is no difference in complication rates, with reservations. The first is Albino *et al*. (2010) who suggested radiotherapy can be delivered with no increase in complications, although they stated if a patient has diabetes, smokes or received neo-adjuvant chemotherapy, their complication rate is increased. Halyard *et al*. (2004, p. 389) reported that two of their sample of 15 (13%) had fat necrosis, but concluded TRAM flaps can be irradiated with 'few complications'.

Two of the six studies that illustrate an increased rate of complications post radiotherapy were led by the same author. Tran *et al.* (2000) and Tran *et al.* (2001) concluded reconstructions should not be performed if radiotherapy is delivered adjuvantly, as severe contracture and fat necrosis did arise, illustrating a higher incidence of long-term complications. Rogers & Allen (2002) agree that reconstructions should be delayed in this case, and found an increased incidence of fat necrosis, fibrosis and flap contracture in the group of their sample who received radiotherapy. Williams *et al.* (1997) confirm that fat necrosis was significantly increased in groups who received radiotherapy, and that 11% of patients had fibrosis in the post-operative radiated group, compared with none in the non-irradiated group. The Watterson *et al.* (1995) study similarly concluded radiation post TRAM flap had more fat necrosis and flap loss, although the data are pooled, making it difficult to determine whether radiation was given pre- or post-operatively. Carlson *et al.* (2008) examined flap complications and, although their study did not show any statistical significance between the group who underwent radiotherapy (44%) compared to those who did not (34%), a trend towards an increase was noted. Interestingly, they detail a higher total flap complication

rate for the group who received pre-operative radiotherapy. This group experienced more skin flap necrosis, infection and haematoma. When compared to the group who received post-operative radiotherapy, fat necrosis is less (20% rather than 32%). Sample size is small (25 in the post-operative radiotherapy group and 15 in the pre-operative radiotherapy group), however the authors concluded that radiotherapy has a deleterious effect whether delivered pre- or post-operatively.

In summary, TRAM reconstructions have been identified as associated with no difference in complication rates after radiotherapy (Alderman *et al.* 2002, Anderson *et al*. 2004) or fewer long-term complications than implant reconstructions (Chawla *et al. 2002*, Jhaveri *et al.* 2008), although Alderman *et al.* (2002) demonstrated an effect if the reconstruction is performed as an immediate or delayed procedure, with the former experiencing higher complication rates. These studies, as well as Soong *et al*. (2004) and Tran *et al.* (2011) concluded that giving radiotherapy to the reconstructed breast does not increase the complication rate. Papers that relate purely to tissue-only reconstructions and complication rate, also suggested that radiotherapy has no deleterious effect on long-term complication rate.

Out of the 23 studies that examine whether radiotherapy has an effect on reconstruction, 15 suggested it can be delivered without an increased complication rate and one concludes it can be given with only a few complications. Eight of these studies suggested radiotherapy increased the complication rate experienced after breast reconstruction. One study claimed the implant-only technique of reconstruction is associated with higher complication rates than those made of tissue-only, although another study stated this rate is the same.

All but two of the studies reported data from a single centre and all but one were retrospective in nature, relying on information held within medical notes. This information may not only be incomplete, but may be subject to individual bias by the clinician at the time documentation took place. There was unlikely to have been a general consensus of how marked flap contracture or fat

necrosis had to have been to be noteworthy, and each study may have used different definitions. Only Rogers & Allen (2002) mentioned their description of fat necrosis, which was when the symptom required debridement. Only one study mentions how many surgeons performed these reconstructions and none whether the individual surgeon impacted on complication rate. There is also a wide variety in what is noted as a complication, some include infection, seroma and skin reactions, while others detail only skin loss and flap loss. Moreover, while it is assumed radiotherapy was completed, there is no definite detail about this or if this treatment was ever paused or abandoned.

3.8.1.2 Cosmetic outcome

Cosmetic outcome was identified as a theme in 19 studies. These can be classified further into studies where cosmetic outcome was evaluated by the patient (n=11), studies that were evaluated by doctors (n=5), and studies that included both patient and doctor evaluations of cosmetic outcome (n=3).

3.8.1.2.1 Patient perspective

Seven of these 11 studies concluded that, from a patient's perspective, radiotherapy did not affect the reconstruction. The study led by Jhaveri *et al.* (2008) reported tissue-only reconstructions had better cosmetic outcomes post radiotherapy than implant reconstructions. Despite Shaikh-Naidu *et al.* (2004), concluding radiotherapy had a detrimental effect on breast reconstructions, it should be noted this is in reference to implant reconstructions, as only six of their sample had TRAM reconstructions followed by radiotherapy, and thus this evaluation was not made. While Roje *et al.* (2010) concluded no aesthetic or patient satisfaction differences between different types of reconstruction, they did not specifically mention radiotherapy in their questionnaire; these data are missing. In addition, the numbers in their sample do not add up correctly and data on different reconstructive techniques is pooled. It appears only nine of their sample

received post-operative radiotherapy and it is impossible to interpret which reconstruction these nine received.

Halyard *et al*. (2004) retrospectively reviewed the medical notes of 15 women and concluded that 13 (87%) of this sample rated the cosmetic outcome of their TRAM reconstruction post radiotherapy as 'good' to 'excellent.' This study does not detail if these ratings were drawn from the review of the medical notes, or if the patients were contacted for this information. Huang *et al.* (2006) and Soong *et al.* (2004) asked their cohort to rate cosmetic outcome and reported a 70% and 85% 'excellent' or 'good' response respectively. Similarly Hunt *et al*. (1997) and Zimmerman *et al*. (1998) concluded radiotherapy can be delivered post TRAM reconstruction with excellent cosmetic results. Hunt *et al.* (1997) interviewed their patients via the telephone about cosmetic outcome and reported 84% of their sample rated their reconstruction as 'excellent' or 'good.' The Zimmerman *et al*. (1998) study reported 90% of their sample rated their reconstruction 'excellent' or 'good.' Sixteen patients thought radiotherapy had no effect on cosmetic outcome, three thought radiotherapy improved cosmetic outcome, and one patient thought cosmesis worse as a result of this treatment. Lee *et al*. (2010) studied three groups; those who received radiotherapy pre reconstruction, those who received it post reconstruction and those who did not require radiotherapy. Although this study included tissue reconstructions and implant reconstructions, their results illustrated that those who received radiotherapy pre-operatively reported the worst cosmetic outcome, and those who received radiotherapy post reconstruction had similar results to those who did not receive any radiotherapy. The tissue-only reconstructions were associated with higher satisfaction scores than those with implant reconstructions.

Jhaveri *et al*. (2008) used telephone interviews with patients to measure functional complications and cosmetic results. Their sample of 92 patients all received radiotherapy post reconstruction: 21 women had tissue-only reconstructions and 71 had the implant-only technique. They found 51% of patients with implant reconstructions reported satisfactory cosmesis,

compared with 83% of those with tissue-only reconstructions. There is no control arm in this study and this preferable cosmetic result may not be associated with radiotherapy being delivered.

Shaikh-Naidu *et al.* (2004) used a patient survey with a five-point Likert scale evaluation pertaining to breast shape, breast size, scarring (both on the breast and donor site) and breast sensation. They reported radiotherapy post reconstruction did have an overall negative effect on patient satisfaction scores about cosmetic outcome when using these measures, however TRAM reconstructions were rated higher by patients than implant ones. Interestingly, they noted cosmetic satisfaction to be greatly influenced by the presence of a nipple-areola complex. Adesiyun *et al*. (2011) used a similar scale and found no difference in patient's general or aesthetic satisfaction for those who had or did not have radiotherapy post reconstruction. Despite this study analysing results for the different reconstructive techniques separately, there were too few patients in each group to have statistical power.

Moscona *et al*. (2006) reviewed responses from 101 patients post TRAM reconstruction and found 86% were satisfied with their results when clothed, 48% were satisfied when naked, spouses' satisfaction was 82% and 90% of the sample had found no change in their sexual attraction. Younger women, less well-educated women and smaller-breasted women were more satisfied with results. Moscona *et al*. (2006) reported those who had radiotherapy (number not specified) were significantly less satisfied with their aesthetic results, especially the touch sensation. Data in this study were pooled and it is impossible to decipher if radiotherapy was delivered and if so, whether this was in the pre- or post-operative setting. In addition the authors did not use a validated patient reported outcome measure.

3.8.1.2.2 Medical perspective

Three papers (Chawla *et al*. 2002, Anderson *et al.* 2004, Wong *et al*. 2008) established cosmetic outcome purely by the physician retrospectively reviewing medical charts and notes, identifying any comments or complaints from the patient or healthcare professional. There is no reference in any of

these studies about completeness of the records under review, nor how many physicians reviewed these clinical notes. Rogers & Allen (2002) and Spear *et al.* (2005) used photographs to assess cosmetic outcome. In an attempt to reduce individual variability, cosmesis was either scored as 'good/excellent' or 'fair/poor', or numerical values were assigned to individual reconstructions. None of these studies solely examined the cosmetic outcome of breast reconstruction post radiotherapy; they also examined other themes identified in Table 3.2.

The Chawla *et al*. (2002) study was concerned with measuring complication rates and cosmesis for patients with TRAM and implant breast reconstructions when radiotherapy had either been given pre- or post-operatively. There were only 30 patients who had TRAM reconstructions, and only 16 of these received radiotherapy post-operatively. The cosmetic outcome of the TRAM reconstructions was deemed significantly better than the implant-only ones, and 90% of those who experienced radiotherapy post reconstruction had 'good/excellent' cosmetic scores. This study concluded that TRAM reconstructions have satisfactory cosmetic outcomes regardless of pre- or post-operative radiotherapy. It is not clear if the trawl through medical notes had produced more than one cosmetic rating from the patient or if there had been any change in scores by the patient during their follow-up care.

Anderson *et al*. (2004) reported their findings of a sample of 85 patients who received radiotherapy post breast reconstruction, looking initially at complications, with their second endpoint being cosmetic outcome. Thirty-five of these patients had TRAM reconstructions; 50 had implant reconstructions. The physicians gauged cosmetic outcomes of the reconstructions and found similar results for the two groups, although they identified that, if a complication had occurred post-operatively, the TRAM flap did not have any adverse cosmesis, whereas if a complication was experienced post implant reconstruction, there was a significantly worse cosmetic outcome. It is not mentioned how many physicians reviewed medical notes to establish cosmetic outcome, or how many surgeons had operated on the sample.

A strand of the work by Wong *et al.* (2008) was physician-assessed cosmetic outcome post breast reconstruction and radiation therapy. This was only managed in 63% of the sample and occurred at different times during the follow-up period. Wong *et al*. (2008) neither defined categories for 'good', 'excellent' or 'fair', nor did they structure the assessment, resulting in some reconstructions being judged on their cosmetic outcome after corrective surgery. They decided to abandon this strand of the research, as there were insufficient values for analysis.

Rogers & Allen (2002) devised a more robust method to compare cosmetic outcome in their study that was solely concerned with DIEP flap reconstructions. They examined photographs of 10 reconstructions before and after radiotherapy, and matched them with before and after photographs of 10 patients who did not receive radiotherapy. The photographs were randomized and blindly evaluated by eight physicians using a five-point scale evaluating symmetry, aesthetic proportion and the appearance of the superior pole of the breast. All three measurements scored statistically significantly worse for the irradiated arm of the study; they concluded DIEP flap reconstructions should be delayed until after radiotherapy is delivered.

Spear *et al.* (2005) found similar results from their study when they compared photographs of TRAM flap reconstructions. Sixteen physicians who had been blinded to the type of surgery judged them for cosmetic outcome, symmetry, flap contracture and hyperpigmentation. Their sample of 171 patients post TRAM flap were divided into three groups; those who had radiotherapy and then a TRAM reconstruction (n=42), those who had a TRAM reconstruction and then radiotherapy (n=38); or the control group who only had the reconstruction (n=91). The group with the best cosmetic outcome measures was the control group, followed by the group who had received radiotherapy pre reconstruction. The group with the least good cosmetic outcome measures was those who received radiotherapy post TRAM surgery, leading to the conclusion that TRAM reconstruction should be delayed for those requiring radiotherapy. All TRAM reconstructions had been performed by the senior author of this paper and there is no detail on how the reviewers

assigned the cosmetic categories of 'poor', 'fair', 'good', or 'excellent' to the photographs.

3.8.1.2.3 Both patient and medical perspective

All three of these studies concluded that radiotherapy did not affect cosmetic outcome. Mosahebi *et al*. (2007), which used a patient satisfaction survey that used a Likert subscale, found patients satisfied with all types of reconstruction and the DIEP flap technique achieved a better cosmetic outcome when compared to the other implant reconstructive techniques. Physicians who had not been involved in the care of these patients used a comprehensive seven-category Likert subscale assessment of cosmesis in addition to breast tonometry where comparisons were made and compared with the contralateral breast. In addition to this, a breast care nurse rated cosmesis through the use of photographs. The studies conducted by Proulx *et al.* (2002) and Mehta & Goffinet (2004) also used subjective judgement of cosmesis by physicians but included the patient assessment also. The former study mentions the plastic surgeon and the patient assessed cosmesis in relation to skin texture, in addition to shape, size and colour of the breast. The latter study gives no detail of how cosmesis was rated, just that at the last appointment both rated this as 'good'.

To summarise, of the 19 studies pertaining to the cosmetic outcome of tissue breast reconstructions, 12 deemed radiotherapy had no effect, four regarded it diminished cosmetic outcome, one reported tissue reconstructions fared better post radiotherapy than implant reconstructions, one study chose to abandon this theme due to insufficient data and one study did not ask about effects of radiotherapy.

While some studies used categories or Likert scales, there is no detail of how others graded cosmesis. There is also no detail in many papers as to whether the clinician who performed the operation ranked the result and scanty information that relates to the content of questionnaires given to patients to complete. For those papers, which used a number of assessors,

individual variability may be present despite the use of predetermined categories.

3.8.1.3 Acute/ immediate side effects

Acute or immediate side effects were considered to be those experienced in the post-operative phase such as infections, skin reactions and wound healing problems. Eight studies contribute to this theme. Soong *et al*. (2004) reported only two women (8%) had grade two acute skin reactions post radiotherapy, and the rest of the women (92%) had grade one skin reactions. They concluded post-operative radiotherapy on reconstructions is well tolerated and not associated with an increased risk of acute complications. Lee *et al*. (2010) class early complications as those that occur within 90 days post-operatively, and found the lowest rate of early complications were those post tissue-only reconstruction who did not receive radiotherapy (10.5%). The parallel group who received radiotherapy post-operatively experienced 11% early complication rate and those who had received radiotherapy pre-operatively had a rate of 21%. In the post-operative radiotherapy group, the tissue-only reconstructions experienced the least early complications (11%) and those post implant plus tissue reconstruction experienced the most (20%). Thus, patients with tissue-only reconstructions who received radiotherapy had slightly higher early complication rates than those who did not experience radiotherapy.

Hanks *et al.* (2000) explored acute effects of post-operative radiotherapy on TRAM reconstructions. Their retrospective sample of 25 was studied for the incidence and degree of erythema and desquamation on the skin. Erythema was categorised as mild (developed in 12 patients, 48%), moderate (developed in 10 patients, 40%) or brisk (developed in three patients, 12%). Ten patients (40%) developed desquamation; of these 50% developed dry desquamation and 50% moist desquamation. Hanks *et al.* (2000) concluded post-operative radiotherapy is not associated with an increased incidence of acute side effects and is well tolerated.

Similarly, the acute effects of radiotherapy on TRAM breast reconstructions have been identified as well tolerated and manageable (Mehta & Goffinet 2004, Halyard *et al*. 2004, Sitathanee *et al*. 2005, Huang *et al*. 2006). Mehta and Goffinet (2004) examined 22 patients post radiotherapy after TRAM reconstruction and discovered 66% did not need any treatment breaks. Only 10% developed desquamation and 30% developed grade II erythema. Halyard *et al.* (2004) retrospectively assessed 15 women for surgical complications, acute and chronic side effects of radiotherapy on TRAM reconstructions. Nine patients developed mild erythema, two developed moderate and one severe erythema. Six patients developed dry desquamation. The Sitathanee *et al*. (2005) study documented three of their sample of 10 developed erythema or mild skin hyperpigmentation, four developed moderate hyperpigmentation and three patients developed skin desquamation, again finding that irradiating TRAM reconstructions is not associated with increased acute complications or the need for treatment breaks. Huang *et al.* (2006) compared acute and long-term effects for those patients who had radiotherapy with or without TRAM flap reconstruction. Their results show 74 out of the sample of 82 (90%) of those who received radiotherapy post TRAM developed grade 1 radiation dermatitis compared to 93 of the sample of 109 (85%) of those who had radiotherapy with no reconstruction. Likewise, 7 of 82 (9%) experienced grade II dermatitis compared to 13 of 109 (12%), and 1 of 82 (4%) experienced grade III dermatitis compared to 3 of 109 (3%). These studies suggested radiotherapy post TRAM reconstruction is well tolerated and not connected to increased complications.

The last paper to discuss this theme is Tran *et al*. (2001). Here, those who experienced radiotherapy pre and post TRAM reconstruction. Once more results showed rates of early complications were not statistically different between these two groups.

In summary, these eight papers all concluded that early complications do occur for patients who receive radiotherapy post TRAM flap reconstruction, but they are well tolerated and manageable. This is expected as they are

considered common side effects of radiotherapy that do not differ according to the operation a patient has undergone. The majority of these studies used a retrospective review of the medical notes to source effects of radiotherapy and only three studies mention using the Radiation Therapy Oncology Group (RTOG) toxicity scale.

3.8.1.4 Co-variables

Nine studies discussed co-variables; five of these are within the arena of tissue-only reconstructions, the remaining four studies discuss this in both tissue and implant reconstructions. The studies referred to the effects co-morbidities had on complication rate. While about a third of these studies chose to use the sub- categories 'minor' and 'major' complications, the rest grouped all complications together. Minor complications included infection, wound problems and haematoma, while major complications referred to the need to re-operate, fat necrosis, hernia, flap loss or flap contracture.

Watterson *et al*. (1995) was the first published study to examine risk factors associated with complications post TRAM flap reconstruction. Smoking, prior radiotherapy, abdominal scarring and obesity were significantly associated with a higher complication rate. Diabetes, age of patient (over 60 years) and hypertension were not found to affect complications.

Hanks *et al*. (2000) examined factors of prior chemotherapy, prior radiotherapy, smoking, the incidence of fat necrosis, and relationship to an increased skin reaction (erythema or desquamation) around the TRAM flap reconstruction for women receiving radiotherapy. They discovered none of these factors had an effect on the skin.

Rogers & Allen (2002) matched patients who had received radiotherapy with those who had not in order to compare complication rates and cosmesis. They also matched age, Body Mass Index (BMI) and, where possible, smoking status. They found that patients who smoked may be more likely to have fibrotic change in the breast, and that obesity may contribute to poor

outcome, although the study stated these are not consistent risk factors. The authors commented that it seemed almost unfeasible to identify a formula in order to recognise which patients would be most susceptible to develop flap contracture, fibrosis or fat necrosis.

Makmur *et al*. (2003) studied 33 women who underwent DIEP flap reconstruction. Most complications occurred in patents over 50 years, and reported that most of their sample of women from Singapore were non-smokers and not obese. Albino *et al.* (2010) similarly found that increasing age added to complication rate in women post radiotherapy and autologous tissue reconstruction. They found diabetes, smoking and preoperative chemotherapy were associated with statistically significantly higher rates of complications.

Chawla *et al.* (2002) concluded TRAM reconstructions have a satisfactory cosmetic outcome regardless of pre- or post-operative radiotherapy, but also examined the patient-related factors of smoking, diabetes or peripheral vascular disease (PVD), and reported that none of these factors predicted a higher complication risk. The authors point out that less than 2% of their sample had diabetes or PVD, so analysing these factors was difficult. Ten (21%) of 48 were smokers, and yet, despite this small sample number and a non-statistically significant result (p=0.15), the authors still reported a trend for these patients to have a worse cosmetic outcome with half reporting a 'fair/poor' cosmetic score compared to 26% of non-smokers. This study detailed 60% of smokers had implant-only reconstructions, so it can be assumed that 40% of those who experienced the TRAM reconstruction smoked. There is no other breakdown however, so it is not known how many of the patients who had the TRAM method of reconstruction experienced complications, a worse cosmetic outcome, or how many of these were given radiotherapy.

The prospective, multi-centred trial that Alderman *et al*. (2002) undertook initially described and compared complication rates of three different breast reconstructions. They defined 'complication rate' as an occurrence that

required additional treatment outside of the norm. The authors also evaluated whether BMI, smoking status, age, timing of reconstruction and if the patient had experienced radiotherapy or chemotherapy had any significant effect. Of the sample of 326, 144 (44%) were post TRAM reconstruction. The results concluded that patients who have reconstructions at the time of mastectomy are twice as likely to have complications as those who have a delayed procedure. A higher BMI was also linked to a statistically significant increase in complications. However, patient age and smoking status were not found to affect this. Pre- or post-operative radiotherapy also had no significance in relation to either total (p=0.08) or major complication rate (p=0.07), although a trend was demonstrated for those post implant-only reconstruction. The post-operative variable of radiotherapy is grouped together with all reconstructive techniques, and so it is not possible to untangle how many of the TRAM flap reconstructions received post-operative radiotherapy and any effects this had. The authors identified chemotherapy was associated with more major complications in TRAM flap procedures, but it is not clear if this chemotherapy was delivered pre- or post-operatively.

Roje *et al.* (2010) found obese patients and those post radiotherapy are statistically significantly more likely to experience complications, and that smoking and increasing age was not a risk factor. However only nine of their sample experienced post-operative radiotherapy, so this was likely underpowered to detect a difference.

Berry *et al*. (2010) reviewed a raft of patient variables during their retrospective review and their data illustrated when referring to autologous tissue reconstructions, radiotherapy, smoking, increasing age, hypertension and previous chemotherapy were not statistically significant predictors of complication rate, however a BMI of over 30 did significantly predict re-operation rate.

In summary, Watterson *et al*. (1995) found smoking, previous radiotherapy, abdominal scarring and obesity related to a higher complication rate, and diabetes, age and hypertension do not. In contrast, Hanks *et al.* (2000) did

not find smoking, chemotherapy or radiotherapy related to their complication outcome measure of an increased skin reaction. Roje *et al*. (2010) stated radiotherapy and an increasing BMI does increase complication rates but that smoking does not when referring to TRAM reconstructions. Berry *et al.* (2010) concurred that BMI effected complication rate, but did not provide similar evidence for those who smoked, increasing age, those who had hypertension, or who received chemotherapy or radiotherapy.

Chawla *et al*. (2002) deduced co-morbidity factors of diabetes, PVD and smoking did not have effect on reconstruction-complication risk, although the authors claimed analysis of the first two factors problematic as very few of their sample had either of these. Alderman *et al*. (2002) similarly found no relationship with smoking to complication rate, and added patient age, radiotherapy and chemotherapy to this list of irrelevant factors. An increase in BMI was, however, shown to affect complication rate. The data relating to the co-morbidities within these studies were however pooled, leaving it impossible to decipher the detail of which reconstruction was performed with which patient co-morbidity. Rogers & Allen (2002) rather tentatively suggested that a higher BMI and smoking may increase complications, while Albino *et al.* (2010) conclude increasing age, those with diabetes, those who smoke and those who have received preoperative chemotherapy are all exposed to a higher risk of complications. Makmur *et al.* (2003) found a relationship between increasing age and complication rate.

On the whole, the studies use the same definitions for complication rate, although some use sub-categories of major and minor. The nature and severity of complications ranged from those short-term and self-limiting, such as infection and wound problems, to longer-term issues such as fat necrosis, flap contracture and hyperpigmentation. None of these studies discussed how complications impact the patient, or how the patient felt about having them. The only exceptions are two papers where authors include excessive pain as a complication. There may have been individual variability between the studies in relation to the threshold where one assessor noted something as a complication and one did not; there may not have been definite

instructions as to how much fibrosis was required before it was deemed a problem. Although blinding of the interventions (experimental and control) to patients and medical staff involved in the studies was undertaken in some studies, others either were not or this detail is lacking. One study used junior doctors and medical students to assess complications, and, while using someone separate could reduce bias, these doctors may have known that the chief author of the paper was the surgeon who had performed all the operations in this sample.

As shown in Table 3.3, eight of the nine studies in this theme discussed smoking. Three concluded it did affect complication rates and five stated it did not. Six studies looked at increasing age; two agreed it affected outcome, four argued it did not. All five studies that reviewed BMI agreed this did affect complication rate, and one of the three studies that examined patients who had diabetes concluded the same. Two of those who studied radiotherapy thought it did influence the complication rate, and three did not. The majority of these studies gained their information from a retrospective review of the notes; this work has not been subjected to a randomised controlled trial. Essentially there still remains confusion within the field of co-morbidities.

Table 3.3 Summary matrix of studies examining co-morbidities.

Authors	Smoke	Age	BMI	BP	Diabetes	Rx	Cx	Abdominal scars	PVD	Timing
Albino *et al.* (2010)	✓	✓			✓		✓			
Alderman *et al.* (2002)	✗	✗	✓			✗	✗			✓
Berry *et al.* (2010)	✗	✗	✓	✗		✗	✗			
Chawla *et al.* (2002)	✗				✗				✗	
Hanks *et al.* (2000)	✗					✗	✗			
Makmur *et al.* (2003)		✓								
Rogers & Allen(2002)	✓	✗	✓							
Roje *et al.* (2010)	✗		✓			✓				
Watterson *et al.* (1995)	✓	✗	✓	✗	✗	✓		✓		

Key:

✓ – effect on complication rate; ✗ – no effect on complication rate

BMI – Body Mass Index; Rx – radiotherapy; Cx – chemotherapy; PVD –peripheral vascular disease

3.8.1.5 Re-operation rates

This theme was identified in five studies. Losken *et al.* (2004) investigated the number of secondary procedures and adjustments required to fully complete the breast reconstruction up to and including nipple reconstruction, and to explore what factors impact upon this process. Secondary procedures were defined as any surgical revisions required to the reconstructed breast, the contralateral breast or the donor site. The authors described a sample that consisted of 888 patients post breast reconstruction; 643 TRAM reconstructions and 245 reconstructions using other techniques. The paper detailed 381 (44%) were immediate reconstructions performed at the time of the mastectomy and 499 (56%) were performed as a delayed procedure. These data seem incomplete as these figures total 880 and not 888. Losken *et al.* (2004) identified that women who suffered any complications required the most additional procedures (re-operations) in order to complete the reconstruction to their endpoint of nipple reconstruction. They also reported those who had a delayed reconstruction experienced higher re-operation rates than those who had an immediate reconstruction. The paper suggested women who had TRAM reconstructions had a higher rate of secondary procedures when compared to those post implant or tissue and implant techniques, and that 21% of these revisions were associated with the donor site.

The Losken *et al.* (2004) study demonstrated that a larger number of procedures are required in order to complete the reconstruction if radiotherapy is given, and that radiotherapy significantly impacted on the need for further surgical adjustments. Caution should be taken with this, however, as these data were pooled and it was impossible to identify which techniques of reconstruction had radiotherapy. This study concluded with a proviso stating secondary procedures are not necessarily an adverse event; they are simply a way of attaining the best cosmetic outcome.

Wong *et al.* (2008) studied the frequency of major corrective surgery, such as complete revision of reconstruction, surgical intervention for infection, significant scar tissue or removal of implant, for those post radiotherapy and

breast reconstruction. They found those patients after implant-only reconstruction required a greater input of corrective surgery than those who had a non-implant reconstruction technique (40% versus 9%, respectively) for the period one to 28 months post radiation therapy. Six months post completion of radiotherapy, none of their sample post non-implant reconstructions required corrective surgery, compared with 23% post-implant reconstruction. Similarly, at one-year post radiotherapy, 4% of those with non-implant reconstructions required corrective surgery, compared with 29% of those with implant reconstructions. In this study, 62 patients had an immediate breast reconstruction using various techniques followed by radiotherapy. Authors group TRAM and LD flap reconstructions (where no implant was used) together for the tissue-only sample. In total, there were five patients post non-implant reconstruction that required surgery in contrast to 11 patients who had implant reconstructions. The authors concluded that this increased risk should be communicated to those considering implant reconstruction followed by radiotherapy. Although minor corrective surgery, such as release of capsular contracture and excision of fibrosis or fat necrosis, did not qualify for inclusion in this research, the authors reported a higher incidence of this in the tissue-only group (29% versus 13%, p=0.3).

Rusby *et al.* (2010) also compared autologous reconstructions with implant reconstructions with the focus on re-operation rates that occurred as planned procedures. Using a sample of 110 immediate breast reconstructions, (50 tissue-only, and 60 tissue and implant or implant-only), the number of corrective surgery procedures required within the first five years was documented. Although not statistically significant, the study illustrated 75% of patients with autologous reconstructions and 87% of those with implant reconstructions experienced at least one further operation. The re-operation rate decreased with time, although neither group reached zero by the fifth year. This study also examined the effect of radiotherapy on re-operation rates. Although the paper reported 11 patients received radiotherapy pre-reconstruction and 26 received it post-reconstruction, these groups are clustered together for the analysis, making it impossible to decipher which type or technique of reconstruction had radiotherapy and the timing. Rusby *et*

al. (2010) demonstrated no statistical significance in re-operation rates for those who had received radiotherapy pre or post reconstruction when compared to those who had no radiotherapy. From their data it is impossible to determine the reason for re-operation; if it is to gain better symmetry, to exchange an implant or to combat ill effects of treatment.

The study conducted by Albino *et al.* (2010) analysed the medical notes of 76 women who had received radiotherapy post autologous breast reconstruction, identifying re-operation rates for post-irradiation changes. They noted post-irradiation complications in 53 of their sample (70%), and 36 patients (47%) required further surgery. There is no detail of what these complications were or if they were serious, just that they required re-operation. They concluded radiotherapy can be delivered safely post tissue-only reconstruction, although suggested those with specific risks such as co-morbidities should be informed of higher complication rates.

The final study that discusses re-operation is Watterson *et al.* (1995). This study identified 78% of a sample of 556 patients post TRAM reconstruction had further surgery, with the mean number of procedures 1.5 (range 0–24). Sixty-three per cent underwent surgery for scar revision, modifications of the flap, liposuction, mastopexy or implant placement, and 73% of their sample had elective procedures to the contralateral breast to improve symmetry. Only 27% of their original sample (n=198) had immediate TRAM flap reconstructions and it is unclear from this study if radiotherapy was delivered pre- or post-operatively.

In summary, there is no consensus between the five papers that investigate the theme of re-operation rates for those receiving radiotherapy post breast reconstruction. The Losken *et al*. (2004) study findings illustrated a higher re-operation rate for those post TRAM reconstruction, although data were pooled and re-operation included more cosmetic operations such as nipple reconstructions. The Wong *et al.* (2008) study focused on complications rather than cosmetic operations and showed a higher percentage of re-operation procedures were required for those post-implant reconstruction.

Rusby *et al.* (2010) suggested a slightly higher, but not significantly so, re-operation rate for irradiated patients with implant reconstructions, and no difference in re-operation rates for those who received radiotherapy either pre or post reconstruction versus those who never received radiotherapy. It is not clear whether these re-operations were for cosmetic benefit or to alleviate complications experienced. The study conducted by Albino *et al*. (2010) concentrated on tissue-only reconstructions and, although it gave no information that related to types of complications, found 47% of their sample required additional surgery. Watterson *et al*. (1995) reported a re-operation rate of 78%, mainly performed to improve cosmetic outcome. In the majority of these papers it is not clear whether these re-operations are to achieve a superior cosmesis or to combat complications of treatment, as authors have grouped all additional operations together. Cosmetic operations reflect a choice the patient has made about further surgery; what they are willing to undergo and what they deem to be important. The difference between this type of operation when compared to unplanned surgery necessary to combat major complications should be reported.

3.9 Discussion of findings from the scoping review

The literature identified discussed the effect radiotherapy has on immediate TRAM/DIEP breast reconstructions. Five themes were identified:

Long-term complications experienced by women post radiotherapy and breast reconstruction. These complications are fat necrosis, fibrosis, flap volume loss and flap contracture. Essentially eight of the 23 studies conclude that post-operative radiotherapy does increase the long-term complication rate, so the majority (15) of the studies report it does not affect this.

Cosmetic outcome. Once more the research appeared to be in favour of there being no detrimental effect to the reconstruction if radiotherapy is given; a viewpoint shared by both patients and clinicians. Some studies included a number of the identified themes, for example, Spear *et al.* (2005) interlinked the two themes of long-term complications and cosmetic outcome. They

concluded that, although long-term complication rates do not differ if radiotherapy is given or not, a delayed reconstruction should be recommended in order to avoid worsening cosmetic outcomes post radiotherapy.

Acute/immediate side effects. These were defined as infections, skin reactions and wound healing problems. All eight papers which reported this theme agreed these effects are more common post radiotherapy and breast reconstruction. This is expected, a side effect of this treatment about which patients are informed.

The first three themes of this scoping review appear to demonstrate consistent findings. Firstly, it could be emphasised that the evidence states radiotherapy does not affect long-term side effects or cosmetic outcome, but it does mean acute/immediate side effects are more common. The last two themes contain more conflicting research.

Co-variables. There was most discord in the studies investigating the co-variables of smoking and those probing the effects of an increasing patient age, so no conclusions can be drawn concerning an effect on complication rate. Research investigating other co-variables discussed was also in disagreement, although individual studies were fewer in number. The effect of the identified co-variables on complication rate for those undergoing immediate breast reconstruction is therefore unknown.

Re-operation rates. Again there appears to be no consensus in the papers that explored this, and it is unclear whether the re-operations are because of complications or whether they are performed to improve cosmetic outcome.

3.10 Conclusions drawn from the literature

This gap analysis found no qualitative evidence on what women think about this combination of treatment. Despite there being many studies on the effects of radiotherapy on tissue-only, immediate breast reconstructions, the

literature is complex and contradictory in places. In many cases, it cannot be deciphered if radiotherapy was delivered to the patient before or after the breast reconstructive surgery, and in some literature it is not detailed which breast reconstructive technique was performed.

The evidence from this scoping review was divided into themes, and the majority of papers within three of the five themes appeared to be in agreement in their findings. The issues of co-morbidity and re-operation rates in the setting of timing of radiotherapy remains unclear. It is not known if co-morbidity affects the reconstruction, or if co-morbidity and radiotherapy are interlinked or dependent on each other.

TRAM or DIEP flap reconstructions are long and complex procedures, but patients who have this appear to have fewer complications than those who have implant-only reconstructions, if radiotherapy is required.

3.11 The rationale for this research

The confusion within the literature has serious implications for healthcare professionals and patients alike. Healthcare professionals need be armed with a robust evidence base for practice, and make decisions and recommendations for treatment using a solid knowledge base. They should facilitate decision-making with information from all viewpoints. At present, there is little detailing the woman's experience and evaluation of these procedures. Women are becoming more active in decision making, it is vital they understand the significance and importance of their medical choices (Lee *et al.* 2010), while having access to experience of previous service users.

CNSs are often most accessible to the woman and part of their role is to assist with decisions about treatment. It is therefore imperative that they are armed with accurate information regarding these operations. The potential contribution to knowledge of this study is to add to this subject to enable the woman to make a more informed decision.

The scoping study illustrated the definite need for this research, which will assist and add knowledge. The issues surrounding the literature are numerous and complex, but the salient question is what the patients who have had an immediate autologous reconstruction followed by radiotherapy feel about this combination of treatment, and whether it matters or makes any difference to their life.

3.12 Summary of chapter

Medical literature surrounding the effects of post-operative radiotherapy on DIEP and TRAM flap immediate breast reconstructions is contradictory and confusing. Many studies group the different reconstructive techniques together and provide their conclusions on that basis. There is no clarity on whether this combination of treatment has a detrimental effect on the breast reconstruction and what is illustrated is often from the clinician's perspective. No qualitative studies were found detailing the woman's experience, thus there is no in-depth information on this topic that concentrates on any effects of post-operative radiotherapy from the patient's perspective. This gap in the literature forms the basis of this study. Therefore, the aim for this research study was to establish patient's perspectives of radiotherapy post autologous breast reconstruction, what they feel and experience as a result of treatment.

Chapter 4: Methodology and methods

4.1 Introduction

Having identified a gap in the literature around the experience of women who have undergone post-operative radiotherapy combined with DIEP flap or TRAM free flap immediate breast reconstructions following a mastectomy for breast cancer, as described in the previous chapter, this chapter presents the rationale for the paradigm, methodology and methods chosen to study this. Paradigm refers to a mind-set or belief system that underlies the research approach; methodology describes the specific theory or body of knowledge underpinning the study; and method is concerned with the processes of data collection and analysis used in its conduct. The main healthcare research paradigms will be discussed together with my own philosophical perspective. The ethical considerations, identification of the research sample, use of focus groups, data collection and data analysis using framework analysis will be discussed, together with the steps taken to ensure trustworthiness of the findings.

4.2 Research question

Given that relatively little is known about the experience of women who have undergone this treatment for breast cancer, this study aimed to answer the question:

> *What do women who have had post-operative radiotherapy combined with deep inferior epigastric perforator (DIEP) flap or transverse rectus abdominis musculocutaneous (TRAM) free flap immediate breast reconstructions following a mastectomy think and feel about the experience?*

4.2.1 Aims and objectives

The overall aim of this study was to add to the current body of knowledge in cancer treatment by exploring the experience of women who had undergone post-operative radiotherapy combined with deep inferior epigastric perforator

(DIEP) flap or transverse rectus abdominis musculocutaneous (TRAM) free flap immediate breast reconstructions following a mastectomy for breast cancer, thus developing an understanding of this treatment from the perspective of the woman.

The objectives of the study are to:

- Collect data from women who have had this treatment for breast cancer.
- Analyse the data to identify the key issues relating to this treatment from the perspective of women who have had the experience.
- Place the experience described by this women into the context of what is already known on the subject.
- Make recommendations for practice to support women in the future with information and advice.

In order to answer the research question, the researcher must consider the best ways to collect and analyse the data. Understanding the theory that underpins research and the methods that can be used to obtain and analyse data is essential when designing the study to ensure the aims and objectives remain central to the process.

4.3 Methodology

Methodology is the term used to describe the theoretical underpinning of a research strategy (Weaver & Olson 2006). How the world can be understood is a concept that has changed over time as beliefs and assumptions alter and evolve. In science, the ways in which we come to understand things depend on the researcher's beliefs and values as well as adherence to accepted norms and rules. Undertaking research requires consideration of the research question and how it may be answered, how that knowledge may be acquired, together with consideration of the philosophical perspective from which the researcher views the world. The prevailing sets of beliefs and

practices shared by communities at any given time are called paradigms (Weaver & Olson 2006).

4.3. Research paradigms

Research paradigms are 'a way of looking at natural phenomena that encompasses a set of philosophical assumptions and that guides one's approach to inquiry' (Polit & Beck 2013, p. 387). How knowledge and understanding is gained changes as beliefs, cultures and assumptions change and, although not all research fits into one distinct paradigm, there are currently two main research paradigms in healthcare: positivism and constructionism/interpretivism, often described with the adjectives quantitative and qualitative (Holloway 2008*).*

4.3.1 Positivism

Positivism is primarily based on what can be observed and measured. In research, it is usually associated with detached observation and controlled experiments (Haase & Myers 1988). The central concept is that knowledge comes from the description or explanation of facts, or empiricism. Positivism suggests the world is subject to natural laws that can be observed, described, explained and predicted. In this paradigm, research deductively tests hypotheses developed from observing the world; taking a general theory, and confirming or refuting it (Holloway 2008).

4.3.2 Constructionism/interpretivism

A constructivist/ interpretative research paradigm aspires to understanding rather than explanation, description and prediction; it acknowledges that research can be carried out on conscious beings in a natural and uncontrolled setting (Mackey 2005). Interpretivism suggests that there is no objective reality but multiple realities held by human beings. In this paradigm, research inductively observes patterns to develop theories. Interpretivism is associated with determining quality rather quantity.

4.3.3 Defining the methodological underpinning of the study

This study was aimed at understanding women's perceptions regarding a combination of treatment for breast cancer; what they think and feel. This is a complex human phenomenon, an experience or perception rather than a test or observation of a natural law or hypothesis. To develop an understanding of an experience from the perspective of another requires attention to what the individual describes. This type of research sits within an interpretivist paradigm because of the need to understand the experience rather than empirically measure it. However, it should be noted that recent articles posit the view that research depends on the integrity and transparency of the research methods and philosophy, rather than the dominance of any one paradigm (Weaver & Olson 2006, Bunniss & Kelly 2010). As nothing was previously known about this topic, a qualitative exploratory study was appropriate.

Although the methodology chosen should reflect the most appropriate way to address the research aims, it has also been argued that methodology is fundamentally linked to the researcher's philosophical perspective and view of the world (Haase & Myers 1988, Grix 2004). Conducting studies in clinical practice involves complex systems in a framework of empirical science, which are also associated with beliefs, values and personal experience. My own position is one of pragmatism; taking a 'pragmatic' approach in the selection of the research method best suited to answering the research question rather than necessarily conforming to a methodological orthodoxy (Glogowska 2011). Pragmatist researchers focus on the 'what' and 'how' of the research problem based on the intended consequences or outcomes (Creswell 2013, p. 11). There is a potential using pragmatism to add additional data collection and have a mixed-methods study, however the main gap identified in the literature was the experience from the perspective of the patient. Adding quantitative data collection to a small sample of women describing their experiences was not considered beneficial to this arena of work. Other studies identified in the gap analysis have described some of the medical concerns associated with this combination of treatment and was

considered beyond the scope of this study given the constraints of single-site research within the context of a doctoral study.
The next step was to define the research methods, or tools and processes that could be used to answer the research question, remaining true to the philosophical underpinning of the theory of interpretive research.

4.4 Methods

4.4.1 Data Collection

This study aimed at understanding women's perceptions regarding a very specific combination treatment for breast cancer. For Kvale (2009), if you seek to be familiar with how people understand their world, talking to them is the most appropriate method. Researchers can talk to individual patients in an interview, or groups of patients in a discussion or focus group.

Interviews are considered to be a powerful method for generating descriptions and interpretations to understand another's perspective (Yeo *et al.* 2014). However, an interview is generally a conversation between two people, the participant and the researcher, and it can be difficult to create neutrality (Yeo *et al*. 2014), especially when the structure and purpose of the conversation is 'determined by one party – the interviewer' (Kvale 2009). This can be particularly difficult in healthcare where the researcher can also be seen as a clinical expert, further widening the power asymmetry described by Kvale (2009). Because there was a need to focus the conversation around a very specific topic in which the interviewer could have been seen as expert, a group discussion was considered better suited not only to getting the women to answer specific questions, but also to engage in a mutual conversation around the topic and thereby elicit more information.

A group discussion, or focus group, brings together a small group of people to discuss an event/phenomenon in which they have a shared experience (Kitzinger 2006, Creswell 2013). The aim of the focus group is to encourage the members to interact with each other. Participants present their own views

and experience, but they also hear from the group and can reflect on each other's experience to reconsider their own standpoint (Finch *et al*. 2014). This can refine individual responses to get a deeper, more considered, level of disclosure (Finch *et al.* 2014). The focus group is seen as an efficient way to obtain a 'broad understanding of phenomena from a variety of perspectives' (Parahoo 2014, p. 320).

Much consideration was given to deciding to use focus groups as the research instrument. Kitzinger (2006) suggests focus groups assist in participants studying and being able to elucidate their opinions via a method that is simpler and more straightforward than a one-to-one interview, and Bowling (2002) suggests focus groups are less constraining for participants when compared to one-to-one interviews. Focus groups have been used in nursing research since the late 1980s. They are useful to gain insight into patient-care problems, assess satisfaction and develop instruments (Burns & Grove 2003). Focus groups are a variety of group interview that maximises interaction among the selected participants in order to produce data (Kitzinger 2006).

Focus groups are advantageous in this setting for a number of reasons. They do not rely on literacy levels of participants and can seem less intimidating than one-to-one interviews, thus more participants may agree to attend (Kitzinger 2006). This method can be used when discussing challenging subjects, as it is believed the more confident participants encourage the quieter members by sharing their experiences first, developing a communal support (Kitzinger & Farquhar 1999, Kitzinger 2006). Clarity can also be sought, and more sensitive and complicated subjects explored (Bowling 2002). However, this method does have disadvantages, namely that it is tricky to capture and analyse data where the individual voices may be difficult to identify, and some participants may dominate and even introduce bias (Bowling 2002, Holloway 2008). Thought was given to whether the social dynamics of the focus groups may affect the discussions in either a positive or negative way but, on balance, it was felt that focus groups would be appropriate.

Three separate focus groups were conducted for this research. The literature suggests a number between four and eight people per focus group (Kitzinger 2006, Creswell 2013).

Burns and Grove (2003) and Kitzinger (2006) state the length of time a focus group lasts is between one to two hours and so this was the length of time the sessions were scheduled for. A patient support centre within the grounds of the hospital where the researcher works was used as the venue for the focus group. Using the support centre allowed for a relaxed atmosphere, confidentiality to be upheld and was suitable for groups of people, with the required furniture and facilities already present. Reasonable travel fares were reimbursed to encourage attendance and participants were compensated for volunteering their time, with a payment of a £20 voucher. Payment was not used as an inducement to participate but rather as recognition of the time committed by participants. Light refreshments were also offered at each focus group in order to create a pleasing and welcoming environment.

4.4.1.1 Guiding the discussion

In the same way that a one-to-one interview can be structured to ask specific questions, focus groups can vary in the extent of structure, based on what is already known on a topic, or on how specific the researcher needs the participants to be (Finch *et al*. 2014). From the issues identified in the scoping review (Chapter 3), potential discussion topics emerged and a guide for the structure of the focus group was devised. This was shown to an expert panel of a cross-section of 11 clinicians from the Trust where the researcher works, which included five Consultant Breast Surgeons, two Consultant Plastic Surgeons, two Consultant Oncologists and two nurses (one breast CNS and one Plastics CNS). Expert opinion was sought on issues of importance in relation to complications and if additional items should be added to the discussion guide.

Senior clinical input was invited to facilitate content validity: the process of asking a team of experts their opinion, ensuring the questions asked were

adequate and relevant for the study (Parahoo 2014). The researcher also considered it important that key clinicians within the Trust were aware of the study; if a patient contacted them or was seen in the outpatient clinic, they would be equipped with information which would promote collaborative team working and authenticate the research.

The discussion guide was then shown to thirteen members of the 'Breast Cancer Support and User-Group' at the Trust for their comments to be incorporated prior to the focus groups. These women were emailed the research protocol and discussion guide for their thoughts and comments within a stated timeframe. They were known to the researcher who had facilitated their group meetings for the last 12 years. This step was deemed important in order to check the language used, which would be the basis for the discussions, was understandable to the potential participants and to ensure that no areas of importance to women with breast cancer had been missed. No major alterations were suggested by either panel, apart from the addition of a final question to ask the women to mark on a Likert scale how satisfied or dissatisfied they were overall with the final results of their reconstruction. The Likert scale was added to the data collection in order to better characterise and paint a picture of the participants in terms of their pattern of overall satisfaction of their reconstruction. The Likert scale is an example of an attitude scale and one that has a place in measuring issues such as health-related quality of life (Bowling 2002). This scale was chosen for its simplicity rather than any other quality of life scale, as the researcher felt it would not be too time-consuming for the participants to complete another tool, given that they had already dedicated a number of hours to the study. This pragmatic approach was taken in order to reduce the commitment required to participate in this study from women who have already given their time and shared their experience of a difficult and emotive episode.
It was also decided not to give the participants a quality of life questionnaire (such as the The EORTC QLQ-C30 or the FACT-B) to fill out when they were at home after the focus group because this would require further engagement with this study and potentially exploring emotions in an unsupported setting. To have given them one before the group could have unduly influenced their

discussions during the group. Response rates for questionnaires can be relatively low and with a study population of 14, this could be problematic (Oppenheim 2000) and waste the time of those who completed the questionnaire. There is debate about the value of health-related quality of life questionnaires and their limitation in providing important information for clinical care and the numbers required to infer any meaningful conclusions (Guyatt 1997). The purpose of this study was not to quantify, but to describe the women's' experience.

From the issues identified in the literature, expert and patient input and discussion with the academic supervisors, nine domains were identified for the focus group framework, which encapsulated and incorporated key potential areas of concern that these women may experience (Box 4.1). These domains were all approached in context of the combination of surgery and adjuvant radiotherapy treatment that the women had experienced.

Box 4.1 Domains to guide focus group discussion in the context of the combination of surgery and radiotherapy

Practical issues – e.g. clothing, childcare
Physical implications – e.g. arm problems
Social implications – e.g. has the experience affected social being
Emotional implications
Relationship and sex issues
Body image issues – e.g. clothing, related to the radiotherapy or reconstruction?
Anxieties related to cancer
Issues with affected skin
Time dimension – to identify if these issues are progressive or resolving

The focus groups were started with an explanation by the facilitator that the purpose was to explore the participants' experience specifically of this combination and sequence of treatment. Phrases such as 'do you do anything differently' and 'how do you feel about the combination of treatment in this order' were used repeatedly during the group to prompt personal

experience and opinion and focus on the topic of interest. To finish the focus group there was a brain-storming session to allow the women to share what would have improved the care they received and a question on how would they advise the professionals as to the best approach of information-giving regarding this combination of treatment. At the end of each focus group, the researcher specifically asked the participants if they had any other issues regarding their experience of post-operative radiotherapy following immediate autologous reconstruction. The participants were then asked to rate how satisfied they were with the final result of their reconstruction using a Likert scale. The option of the follow-up telephone call was offered, which enabled participants the opportunity to be contacted if they wished one week later at a mutually suitable time.

4.4.2 Sample

The women invited to participate in the study were those who had received this combination of treatment (DIEP/TRAM plus radiotherapy) in the Trust where the researcher works. This type of sample of potential participants is described as a convenience sample, allowing the sample to be made up of the most conveniently available people (Polit & Beck 2013, Ritchie *et al.* 2014). It was stipulated that the participants must be between one and five years post-surgery, thus the TRAM/DIEP operations should have taken place between 2008 and 2012. This is because the focus of this research was not to investigate the commonly and well-documented immediate effects of radiotherapy, such as redness, rather the long-term effects of the treatment combination of the reconstruction, some of which do not occur until one year post treatment (Watterson *et al.* 1995). During this time period, four Consultant Plastic Surgeons performed these surgical procedures.

4.4.2.1 Inclusion criteria

- Women with breast cancer post TRAM and DIEP immediate breast reconstruction who were operated on at this London teaching hospital between 2008-2012 (between years 1-5 post-operative)

- Women who had radiotherapy post-operatively at this London teaching hospital
- Women who gave informed written consent

4.4.2.2 Exclusion criteria

- Men
- Women who had pre-operative radiotherapy
- Women who had other forms of reconstructions, for example with implants
- Women who had delayed breast reconstruction
- Women who were less than one year post completion of post-operative radiotherapy
- Women with breast cancer recurrence or metastatic disease
- Non-English-speaking women (there was no budget for translators and the researcher felt it inappropriate for someone to translate during the focus group as the flow of the discussion could have been compromised)
- Women who failed to give informed written consent

4.4.3 Identification of participants

A database has been in use at the Trust to document and detail surgical procedures performed by all plastic surgeons since 2012. Prior to this, one surgeon held his own incomplete database listing some of the procedures performed between 2010 and 2011. The only other method of sample retrieval was to locate the paper diaries used by the plastic surgery department and trawl through the appropriate and relevant years: the diaries from 2008–2012.

The surgical databases and diaries were searched, and women who had an immediate TRAM/DIEP operation within the appropriate years were noted. Then the hospital-based computer system was used to identify whether the women had attended a post-operative oncology appointment. For these women, the last clinic letters were sourced to establish whether radiotherapy

had been delivered. This last letter was important in deciphering whether the woman was still alive and disease-free, with no localised or disseminated disease. As part of the direct clinical team, the researcher had routine access and was able to search the database and diaries used at the trust in order to identify eligible patients. Thirty potential participants were initially identified.

4.5 Recruitment

The 30 potential participants were approached by the researcher in the form of the participant-information letter (Appendix 3) sent in the post, and the envelope was marked 'private and confidential.' It contained the details of the study, contact information for the researcher, and a tear-off slip with the dates and times of the focus groups. There was also a section for the woman to tick if she wanted to participate but was unable to attend at the suggested times. A stamped-addressed envelope was included in addition to an email address for the researcher to ensure women were able to reply. After one week, if there was no response, the researcher telephoned the woman and sent out a repeat participation information letter. The telephone call was designed to act as a prompt in decision-making and an opportunity to answer any questions. The groups were decided according to individual response on the tear-off slip. After discussion with my academic supervisors, it was thought three focus groups were a sufficient number to cover attitudes and experiences of this cohort of women.

4.6 Ethical considerations

Local research and development (R & D) approval was given by the NHS Trust where the researcher works, and ethical approval was given by the National Research Ethics Service Committee West Midlands – Black Country Research Ethics Committee (Appendix 4). Care was taken to ensure that women who were sent a participant information letter were still alive and well; the Trust follows-up these women for five years post treatment - minimising the risk of contacting a person who was deceased.

Written consent from each participant was given at the beginning of each focus group (Appendix 5). The burden for the women was primarily the time required for the focus group. During the interactions with the women, it was noted that they might disclose real or perceived problems that occurred either during their experience, or as a result of their operation and treatment. They might have divulged inappropriate care or ill effects they continue to experience. Caution was taken by the researcher and a system was operational for the women to gain access to the surgical outpatient clinic for assessment if required. Time was allowed for discussion of pertinent, unexpected issues, and the women were given the option of being referred to the Trust's clinical health psychology department, lymphedema service or the complementary therapist for support. These three departments were informed of the potential referral of these women. The prosthesis practitioner was also informed of this study as there may have been women who wished to be fitted with a breast prosthesis to gain better symmetry after discussions with other women.

If any of the participants reported untoward or 'red flag' symptoms that could have signified their cancer coming back (for example, nodules on the reconstructed breast), the researcher would have recommended and encouraged them to source help from their general practitioner (GP) as soon as possible. No referrals were made or red flag symptoms mentioned throughout the groups.

Although the researcher works within the Trust where these operations took place, this was on a different hospital site and, as such, had no input into their care during the stage of the women's treatment under investigation. This, it was hoped, reduced any ethical issues when conducting research within one's own organisation, or pressure the women may have felt to participate. The women's telephone numbers were listed by name, but stored by the researcher on a password-protected NHS computer. The use of anonymised direct quotations from respondents is an item included on the women's consent form (Appendix 5).

The researcher received guidance as required from the National Institute for Health Research (NIHR) in addition to the King's College London 'Guidelines on Good Practice in Academic Research'. Care was taken to work within the boundaries of The Data Protection Act (1988). Participants were informed they were free to withdraw from the study at any time up to the point of data analysis. All aspects of the study, including results, were treated as strictly confidential, and only the investigator and research supervisors had access to this data. Individual participant's responses were not identifiable and electronic transcripts were password protected. Data were anonymised by an ID number when using quotes.

Although there was no direct medical benefit to the participants, some people appreciate the opportunity to make their experiences and views known, and to participate in research. The sharing of experience that occurred during the focus groups may, therefore, have been beneficial to the participants. The women were also introduced to the patient support centre if they had not been involved in the Centre previously.

4.7 Structure of the focus groups

Three focus groups of four to six women were held at a patient support centre in London over a four-week period in September to October 2013 (Table 4.1). Two were during the afternoon and one in the evening.

Table 4.1 Details of focus groups

Focus Group	Date	Time	Number attending	Participant numbers
1	16 September 2013	2–4 pm	6	1–6
2	18 September 2013	6–8 pm	4	7–10
3	10 October 2013	2–4 pm	4	11–14

4.7.1 Focus group facilitation

Although the researcher was present at the groups, the lead research supervisor, who is also a nurse and who has research experience and familiarity with facilitating focus groups, facilitated the sessions. Bowling

(2002) suggests important characteristics of the facilitator are to be competent in drawing out salient points from the participants, to handle conflict, to coax response from more inactive participants, while establishing a relaxed environment. At the beginning of each session 'ground rules' were constructed by the group, comprising acceptable and non-acceptable behaviour, for example, not interrupting people when they were speaking. It was hoped these ground rules would promote sharing, participation and group dynamics. During the discussions all the participants were encouraged to give their opinion in order that a wide range of views are represented. At the beginning of each group it was reiterated that a consensus was not being looked for and that it is purely the woman's thoughts about the combination of post-operative radiotherapy and their immediate breast reconstruction that are important. The facilitator encouraged group members to participate and acted as a prompt throughout the sessions as she worked through the discussion guide, ensuring each topic on it was addressed and that the focus was on any effects of this combination of treatment.

The facilitator attempted to keep the focus group on the subject relevant to the study and facilitate discussion. The likelihood that some may disagree with others on any effect radiotherapy had on the reconstructions was also mentioned.

At the end of each focus group the researcher and the facilitator met for a debriefing session. This allowed time for discussion of the content of each of the groups in addition to giving an opportunity to feedback any issues to each other. There was an understanding that although the facilitator was the lead research supervisor, that the researcher was very much in charge of the focus groups and the research. Transcripts were also scrutinised by the other two supervisors. It was recognised during this process that the women were discussing a very wide range of issues during the groups rather than focusing on the topic of interest. However, it was not felt appropriate to change the topic guide or the facilitator's questions for subsequent groups as it was evident from the first group onwards that, despite repeated re-focussing, the treatment combination was not a particular concern for the participants.

4.7.2 Focus group process

Prior to the start of each focus group the researcher requested that the participants complete a consent form (Appendix 5) and answered any outstanding questions. All had previously received the patient information sheet (Appendix 3) explaining the purpose of the group was to explore the combination of treatment and this point was reiterated in the introduction to the group, explained that all participants had undergone this combination, and repeated several times during each group. At the end of each focus group the researcher asked the participants outright if there was anything additional they wanted to say solely relating to any impact of having had adjuvant radiotherapy. The researcher then explained the option of the follow-up telephone call. This was an opportunity for the participants to feed back any thoughts they might have on the subject within the following week. The participants signed consent if they wished to be contacted in this fashion, and the researcher documented dates and times these women wished to be contacted along with the numbers they wished to be called on. The consent form incorporated an opt-in/opt-out section for the follow-up telephone call (Appendix 5). At the end of each group, the participants were handed one last question on a piece of paper, asking them to give an overall mark out of 10 for how satisfied they feel about their breast reconstruction. Once this was complete, the researcher met briefly with each participant, in order to reimburse travel costs and give the £20 voucher.

4.8 Data recording

With the consent of the participants, the focus groups were audio-taped in order to allow the researcher to concentrate on the discussion as appropriate. Participants were also asked to complete a brief sheet detailing their demographics of age, ethnicity, any other major illness, their occupation and, if they work, whether they work full- or part-time. Their highest academic achievement was also requested (Appendix 6). These acted as descriptive data at the analysis stage of the research.

The data collected were qualitative data, that is, data that encapsulated the perceptions of what the women perceived about the research questions posed within the context of their focus group sessions.

4.9 Data analysis

The narratives collected through these three sessions were subjected to analysis in order to establish themes and common perceptions in the hope of informing future clinical recommendations and decisions.

Qualitative research methodologies generate large volumes of relatively unstructured data that need to be ordered and deconstructed to reveal the meaning beneath (Van Manen 2006). The analytical process involved taking the complex human experience and transforming it into something useful and meaningful for others. It required the researcher to maintain a balance between developing coherence and structure to the data, and creating a new story, while remaining true to the original account and experiences of the participants (Spencer *et al.* 2014).

The discussion guide was developed to identify the concerns or issues understood to date. It was used to steer the focus group discussions, to ensure that key pre-identified domains were considered and to structure the analytical process for a less experienced researcher (see 4.5). The analytical process began during the focus groups with interpretation of what was being said, and attempted to clarify the information given and explore any reference made to the issues identified,. Each focus group informed the next in an evolving process.

4.9.1 Using Framework Method for analysis

There are a number of research methodologies more readily associated with interpretivism that could have been used to underpin the study theoretically, such as case study, ethnography, grounded theory, narrative research, phenomenology and framework analysis. Framework Method (also known as framework approach and framework analysis) was originally used to assess

policies and procedures from individuals who have experience of them (Srivastava & Thomson 2009). It was considered to be more closely aligned to the aims of the study than phenomenology, which aims to understand the essence of a lived experience; narrative research, which generally reports the life of a single individual; grounded theory, which aims to develop a theory; ethnography, which is concerned with culture; or case study, which seeks to understand a problem or issue using a case as an illustration (Creswell 2013). Framework Method was also deemed most appropriate as, although the scoping review gave indications of what the issues were likely to be, this approach is flexible enough to include new themes as they arose.

For the purposes of this study, Framework Method was used, although it is acknowledged that other approaches would potentially have been valid.

Framework Method was developed as an analytical tool in the context of conducting applied qualitative research in the 1980s (Ritchie & Spencer 1994). Applied research aims to provide outcomes or recommendations around specific issues, often within a short timescale (Lacey & Luff 2009). Framework Method was designed to manage unstructured and unwieldy text-based data allowing flexibility to move between levels of interpretation without losing sight of the raw data (Spencer *et al.* 2014). It has been likened to grounded theory but, although theories may be generated, the primary concern is to describe and interpret what is happening in a particular setting (Ritchie & Spencer 1994). It is considered better suited to research with specific questions, a limited time frame, a pre-designed sample and a priori issues (Srivastava & Thomson 2009). Framework Method has certain key features:

- *Grounded or generative*: it is heavily based in, and driven by, the original accounts and observations of the people it is about.
- *Dynamic*: it is open to change, addition and amendment throughout the analytical process.

- *Systematic*: it allows methodological treatment of all similar units of analysis.
- *Comprehensive*: it allows a full, and not partial or selective, review of the material collected.
- *Enables easy retrieval*: it allows access to, and retrieval of, the original textual material.
- *Allows between- and within-case analysis*: it enables comparisons between, and associations within, cases to be made.
- *Accessible to others*: the analytical process, and the interpretations derived from it, can be viewed and judged by people other than the primary analyst.

(Ritchie & Spencer 1994, p. 176)

Richie and Spencer consider the role of qualitative analysis to be 'essentially about detection', and the tasks of defining, categorising, theorising, explaining and mapping are fundamental to the analyst's role in the detection process (Ritchie & Spencer 1994, p. 176). Framework Method is not suited to detecting patterns in data that covers a wide variety of topics but to well-defined or key issues (Gale *et al.* 2013), such as a specific surgical procedure. It is becoming an increasingly popular approach in health research (Furber 2010, Smith & Firth 2011, Gale *et al*. 2013) and, although more commonly associated with semi-structured interviews, it was designed to also support analysis of focus group data (Ritchie & Spencer 1994).

4.9.2. Analysising the focus groups using Framework Method

Data analysis was carried out using the Framework Method. The data were analysed following the seven steps of analysis first described by Ritchie & Spencer (2004), and clearly described by Gale *et al*. (2013).

4.9.2.1 Stage 1: Transcription

Transcription presents the oral conversations in a written format. There are various forms of transcription; this may be a summary of the event or a verbatim representation. When verbatim, or word-for-word, it is assumed to

be a direct reflection of the research event. Even when a transcription is verbatim it requires a level of interpretation on the part of the transcriber that changes the original event to represent it in a different format. The focus group also contained body language, bodily expressions, hesitation, tone, inference, etc. and, as such, a focus group is over simplified when transferred to words on a page. There are arguments for the researcher to carry out transcription to continue their closeness with the data, however using a professional transcriber can reduce the time taken and potentially minimise errors in the transcribing process. Framework Method does not require the inclusion of conversation conventions such as pauses, or two people speaking together because the content is what is of primary interest (Gale *et al*. 2013).

Audiotapes can be analysed by listening and reviewing and not transcribing, but managing large amounts of data can be difficult with this method. An experienced research transcriber carried out the transcription, which was then checked by the researcher against the taped recording to correct for errors or omissions. This is particularly important in focus groups, where it is not always clear who is speaking. It is much easier for someone who was present at the focus group to assign/confirm the participant speaking or clarify sentences where there are gaps. The transcription was entered on a computer using word processing, which allowed text to be edited rapidly, easily manipulated and safely stored. The anonymised transcriptions were typed and stored in Microsoft® Word ready for the analytical process.

4.9.2.2 Stage 2: Familiarisation with the focus group

Stage two in Framework Method involves familiarisation with the interview. Although listed as the second stage by Gale *et al*. (2013), this process began immediately after the focus group and continued when checking the transcriptions by listening to the tapes and reading the text. This allowed the researcher to maintain closeness with the original research setting and to relive the experience, to gain a sense of the whole, and recreate the original focus group. Building familiarisation with the data helped the researcher to

recall and refresh the experience and 'hear' the voices of the participants clearly. This was a vital stage in the interpretation.

As part of this process, each individual participant's statements were drawn out of the text and constructed as a single narrative in both verbatim and summarised forms, to get a greater sense of the individual components of the story as abstracted from the whole. This formed part of the deconstruction of the narrative ready for the analytical reconstruction of the experience. Each single narrative was further refined as an interpreted case history. Once a deep sense of the complete data set had been developed, the process of structuring the data to demonstrate patterns or themes began.

4.9.2.3 Stage 3: Coding

Textual data can be organised in many ways; from underlining or highlighting relevant statements, to writing statements as notes, to using specially designed computer software. Organising the data is about interpretation rather than the application of tests and mathematical models. Coding the data aimed to classify it and enable it to be compared in a systematic way with the whole data set. Since the focus groups were stored in an electronic format (Microsoft® Word), it was decided to continue electronically with data organisation and manipulation.

Word-processing packages have been used to manage relatively small amounts of qualitative data but tracking and cross-checking data can be difficult, especially across three, relatively long, focus groups. Being able to manage and reduce the large amount of data was a vital part of the analytical process. There is no one tool that has to be used with the Framework Method, and the researcher understood that working with and coding narrative text is possible with Microsoft® Excel® (Meyer & Avery 2009, Hughes *et al*. 2010), thus this was chosen to support the analytical process. Familiarity with, and access to, Excel facilitated its use as the most pragmatic tool to ensure the large volume of data could be managed appropriately. This made the data analysis more accessible to others and provided an effective

audit trail of coding. After familiarisation with the text as a whole and deconstruction to reveal the individual stories, the next step involved reading the transcripts and sorting the statements into the pre-defined domains that had been used to guide the focus group discussions (Box 4.1, p. 69).

At this stage, additional headings/labels were added to the domains to include chemotherapy, radiotherapy, the introduction the participants gave and other, because there was a sense that this data also needed to be captured and stored for easy retrieval (Box 4.2).

Box 4.2 Additional domains

Radiotherapy
Chemotherapy
Introduction
Other

Extracting the statements involved 'cutting' the exact statement from the electronic copy of the focus group text and 'pasting' it into the Microsoft Excel® spread sheet, making sure it was assigned to the relevant participant. Sometimes an additional reference to context was made to help the novice researcher maintain the thread of the story (Table 4.2).

Table 4.2 Example of adding context to extracted statement

Focus Group	Participant	Practical issues – clothing, arm problems, childcare
1	1	*Donor site*: Yes so if I wear something fitted you can see I've got a little bump

Using Microsoft® Excel® it was possible to filter according to participant, focus group or theme, and this enabled the large amount of text to be easily sorted and managed in a way that could be compared systematically to other parts of the data set. This formed part of an open coding system where almost all the text was allocated to one of the pre-identified domains or additional domains ready for the more inductive phase of interpretation of the meaning to reveal the experience without losing data.

4.9.2.4 Stage 4: Developing a working analytical framework

Following the initial coding, the underlying themes began to emerge. These were discussed in supervision and refined as concepts. The six identified themes were, *Being changed, Control, Coping strategies, Normalisation, Information* and, *Trust and faith in healthcare professionals*. It was agreed that the second level of coding would involve applying these codes to the text. This formed the working analytical framework.

4.9.2.5 Stage 5: Applying the analytical framework

The working analytical framework was then applied by indexing the transcripts using the identified codes or themes. Each code is usually assigned a number or abbreviation for easy identification and written directly onto the transcripts. However, computer software can be used at this stage to speed up the process and ensure that the data are easily retrievable (Gale *et al*. 2013). Unlike software programmes in studies using quantitative methods, computers are used to manage and manipulate the data but not for analysis. Microsoft Excel® was used in this study to reorder the data to apply the analytical framework, making it manageable and accessible for researcher analysis.

4.9.2.6 Stage 6: Charting data into the framework matrix

This stage involved taking the verbatim statements from the initial spread sheet, summarising the meaning and charting according to the newly identified themes. Using Microsoft Excel® it was possible to keep the original verbatim statement together with the reduction. This allowed the interpretation to be checked throughout the analytical process and enabled the researcher to keep track of the participant's own words to be used when presenting the data to demonstrate the authenticity of the study. Within each theme, sub-themes emerged to explain the contributing aspects or branches of the theme. The sub-themes were identified in a two-step process, initially by defining the meaning, but these were too large a data set, so a second level of sub-theme was identified (Table 4.3).

Table 4.3 Example of meaning, sub-themes and themes

Participant	Practical issues – clothing, arm problems, childcare issues	Significant statement	Meaning	Sub-theme	Theme
11	I mean even now I couldn't wear as much tight t-shirts because I just feel it doesn't look right, but it's okay, you know. It doesn't bother me that much that I feel like that.	I couldn't wear as much tight t-shirts because I just feel it doesn't look right,	clothes – different	Physical changes	Being changed

4.9.2.7 Stage 7: Interpreting the data

Using the filter feature of Microsoft Excel® it was possible to identify and refine the themes and sub-themes throughout the analysis as a dynamic and iterative process. The themes and sub-themes were often overlapping and interconnected. They were part of the whole experience and were not separate from it. Understanding of the themes and sub-themes changed constantly during the analytical process. Gradually the characteristics and differences between the data were uncovered, and the themes and concepts refined.

4.10 Trustworthiness

The trustworthiness of a study is the measure of its rigour, and demonstrates how thorough and consistent the process of study has been (Holloway 2008). Traditionally, terms such as reliability, consistent and accurate representation of a population, and validity, the measure of what was intended to be measured, have been used to describe credibility or trustworthiness. Qualitative researchers have rejected the term 'validity' in favour of 'trustworthiness', which allows for truth to be seen as a concept that can change over time (Holloway 2008).

There are many ways to establish trustworthiness in qualitative research (Lincoln & Guba 1985). The measures to ensure trustworthiness in this study were: supervision from experienced qualitative researchers, focus groups led by an experienced clinical academic researcher, focus group discussion

guided by a framework developed by an experienced clinician, a group of experts and a group of patients, a recognised analytical framework was used to manage and analyse the data, and the data was readily available in a manageable format for audit.

Respondent validation or member checking has been used in qualitative research as a way of quality control to confirm with the participants what they detailed during the research (Harper & Cole 2012). At the end of each focus group the researcher reiterated that the study's focus was to establish the women's perceptions of the effects of the combination of radiotherapy post-operatively. The researcher summarised what she thought the participants had said on this topic and asked if this was correct and if there was any additional detail they wished to add. This was done to add credibility to the research and to sense-check the data. No participants added anything additional at this point in any of the three focus groups.

It was decided that neither the transcript nor a thematic summary should be returned to the participants for additional member checking. This decision was based upon a number of issues, including that a year had passed since the focus groups had been held and it was thought this time lapse would mean this type of validation may not be meaningful. In addition, it was thought the participants may not have insight into the other participant's behaviour or responses, and as suggested by Fielding & Fielding (1986). These authors suggest respondent validation cannot be used as a form of direct validation, rather that this process would yield another source of data as participants would inevitably have developed their thinking following participation in the group and the passage a further year since their treatment. Member checking is controversial in qualitative research and there is a strong argument for not doing this as if participants disagree with their interview or the subsequent analysis, it is impossible to know which view to include as data (McConnell-Henry *et al.* 2011).

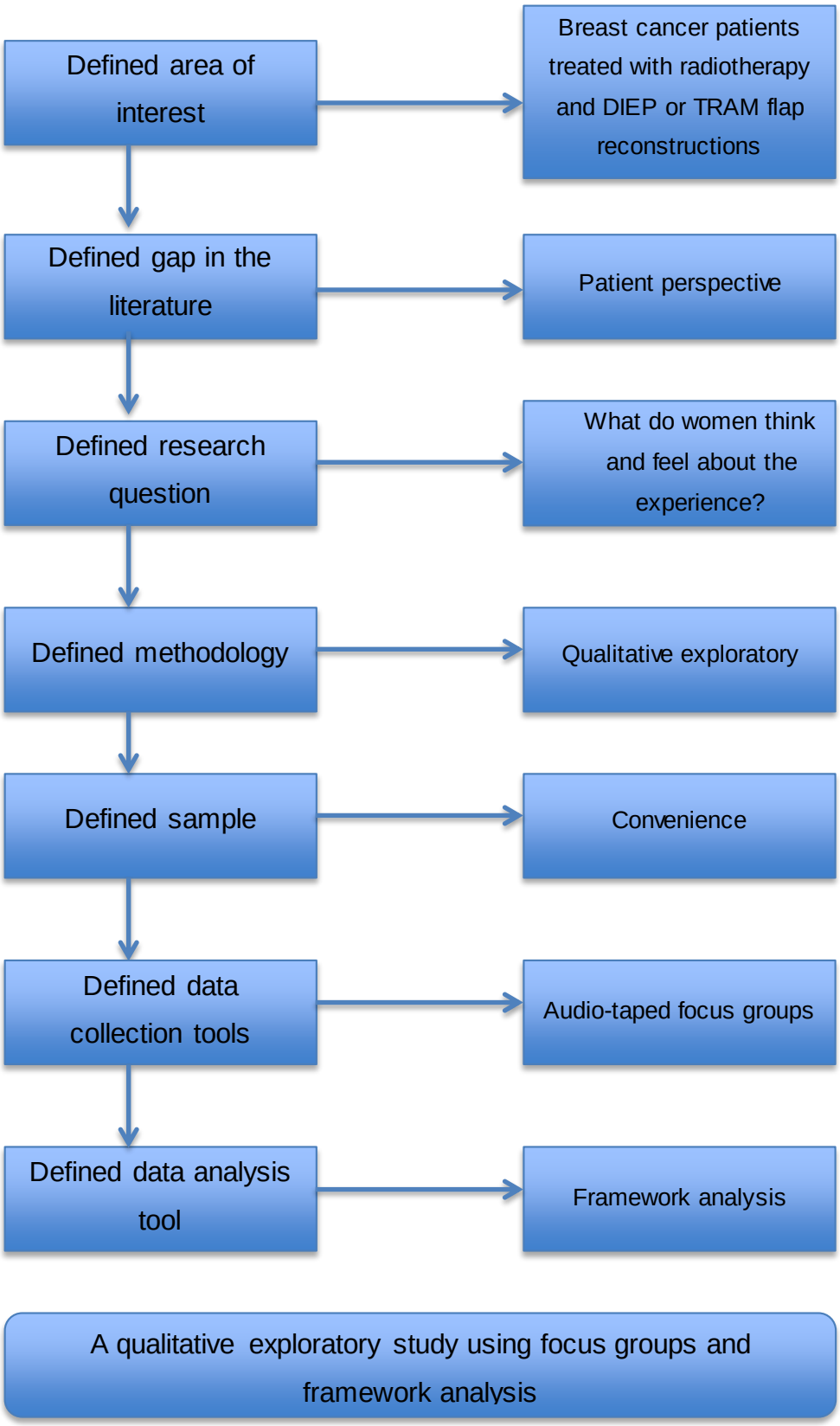
4.11 Steps in research design

The decisions made in the design of the study were carefully recorded to ensure clarity in the process and are shown in Figure 4.1.

4.11 Summary of chapter

This study was conducted within the constructionist/interpretivist paradigm on individuals in the setting of a focus group. Expert clinical knowledge was used to guide the focus groups, but the women who had the combination of radiotherapy plus TRAM or DIEP flap breast reconstructions were also free to discuss what mattered to them. The Framework Method was used to underpin analysis of the study, and the analytical process involved using the seven steps to identify the themes that took the complex human experience and transformed it into something useful for others. The research was conducted within the framework of NHS research ethics, and under academic and clinical supervision, using a recognised method to ensure auditable data and trustworthy findings.

Figure 4.1 Flow diagram of research design process



Chapter 5: Findings

5.1 Introduction

This chapter describes the findings of the study and discusses each of the six identified themes. The findings are presented using the participants' own words in italics to illustrate the theme and the analytical decisions. Individual participants are identified using a focus group number (F) and a participant number (P) to demonstrate the range of discussion between participants and also within the focus groups. The line (L) the statement comes from on the analysis spread sheet is also noted (except for group introductions). Having identified the individual stories within the focus groups, the findings will be presented from the perspective of the individual participant and the study as a whole. All of the themes cut across the pre-identified focus group domains, as described in Chapter 4.

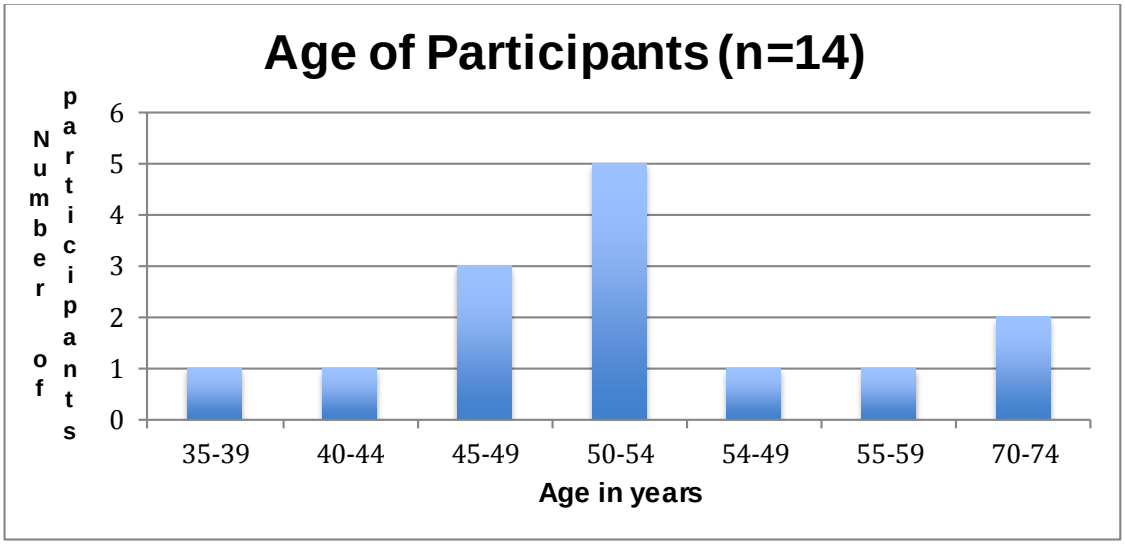
5.2 Description of participants

Thirty eligible women were identified to participate in this study (see 4.6.1). All were sent an initial letter (Appendix 3), 21 were telephoned one week after the letter and 24 were sent a second letter (as per approved protocol). Twenty-five (83%) responded one way or another. Of these, seven declined (28%); two felt they did not qualify, one was unable to participate because of work commitments, one said she was unable to participate due to another (non-breast) operation and three declined without giving reasons. Five did not respond to the letter or telephone calls. Eighteen of the women agreed to participate in a focus group. Of these, four were unable to attend on any of the planned dates. This gave a total of 14 participants over three focus groups. Focus group one lasted 99 minutes, focus group two 91 minutes and focus group three 77 minutes. One participant arrived 28 minutes late. Three of the participants agreed to be contacted by telephone one week after the focus group, as an opportunity to give additional comments.

5.3 Descriptive statistics

The age of the 14 participants ranged from 35 years to 74 years (Figure 5.1). Most (n=8) of the women were aged between 45 years and 54 years.

Figure 5.1 Age of participants



The largest group (n=5) of the participants described their ethnicity as White British, but there was a relatively wide ethnic mix across the groups (Table 5.1). Five of the participants were in paid employment (thee full-time and two part-time), two were students, two retired, two housewives, one in receipt of disability benefits and two were unemployed.

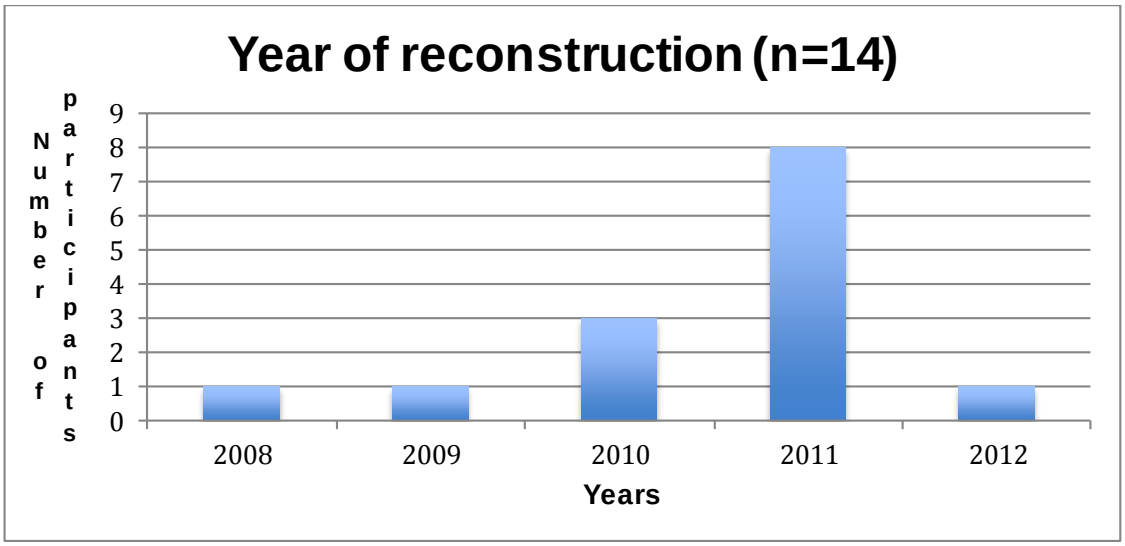
Table 5.1 Ethnicity of participants

Ethnicity	Number of participants (n=14)
White British	5
Indian	2
Other Asian	2
Other white	2
Caribbean	1
Iraqi	1
Pakistani	1

Surgery had been carried out between 2008 and 2012; between five and one year prior to the focus group. Although two participants gave a different year

of surgery in the focus group compared to the questionnaire, which may be associated with having different procedures, the majority (n=13) had the reconstruction at least two years previously (Figure 5.2). Ten of the participants reported having DIEP, but four did not know what surgery they had received. In fact, all the participants had undergone a DIEP flap breast reconstruction, with one having had bilateral DIEP flaps.

Figure 5.2 Year of reconstruction



Radiotherapy was completed between 2008 and 2012; again between five and one year prior to the focus group. One participant failed to answer this question. Where the participants included the months of treatment (n=8), there was a range of between two and seven months between the surgery and completion of radiotherapy, with a mean of four months. Three of the participants said they had other non-cancer related health problems, such as asthma, diabetes, hypothyroidism, ulcerative colitis and raised blood pressure. The highest level of education/academic achievement ranged from none to post graduate. Six of the participants had either a first degree or a professional qualification, such as accountancy or engineering.

The anonymised transcriptions generated a data set of about 46,500 words and 107 pages of narrative text (font size 12, single spacing).

5.4 Major findings of this study; experience in context

The aim of this project was to study women's perspectives of radiotherapy combined with immediate DIEP and TRAM free flap breast reconstructions when used in treating breast cancer. The structure of the focus group was designed to maximise the discussions relating specifically to the experience of this combination of treatments. The participants did not share any major concerns regarding this combination of treatments and furthermore stated they would recommend this sequencing of treatment modalities to others who found themselves to be in the same clinical situation. These findings will be summarised below within the following analysis.

There were some concerns expressed, such as redness and soreness during an immediately after radiotherapy (see below). However, these do not seem to have been major and were transient and not directly related to the combination treatment. Despite repeated probing none of the women in the focus groups reported major complications or adverse events after radiotherapy, or recounted any experiences which were likely to be related to major complications, strongly suggesting that none of the participants had experienced flap contracture or wound breakdown.

Despite the continual prompts from the focus group facilitator, it proved impossible to separate the experience of radiotherapy post reconstruction from the whole cancer experience. This began with the way the women chose to introduce themselves to the group, defining themselves by their cancer diagnosis, this occurred during each of the introductions for all of the focus groups, with the exception of P10 who arrived late and joined the group mid-discussions, for example:

'… I am (name)…I had breast cancer when I was fairly young, well a couple of years ago I was diagnosed. ... And I had three tumours so it was quite aggressive although it hadn't spread …' (F1:P1)

'… I was diagnosed with breast cancer in January 2010 and then following that I had chemotherapy, then I had the reconstruction and then I had radiotherapy following that …' (F2:P7)

'… My name is… and I've had cancer since 2008 …' (F3:P11).

The participant's individual experience of the relevant aspects of treatment was interwoven into their whole story and forms a picture that cannot always be separated into its component parts. It should also be recognised that it is the only experience these women have had, and cannot be compared to other forms of breast cancer treatment. How the findings of this study can be used in clinical practice and relate to the breast cancer literature will be discussed in Chapter 6.

For the women in this study the experience of radiotherapy post DIEP or TRAM reconstruction did not occur out of context of the diagnosis of cancer or the individual woman's life. Breast cancer seemed to reverberate through every aspect of the participant's life, their self-identity, daily routines, family and social experiences. The women detailed that in context of the enormity of their breast cancer treatment, the combination of post-operative radiotherapy post immediate breast reconstruction was not such an issue and it was well-tolerated. This is the first study to report qualitative data on this specific combination of treatment for women. The women shared tips and practical advice with each other in a relaxed and informal manner that can hopefully translate to increasing the patient experience through healthcare professionals addressing the specific needs of these women in a more holistic way.

5.4.1 Treatment complications

Initially there was an attempt to identify complication rates from the narrative of the focus groups. Given the small number of participants in this qualitative study it would not have been possible to make assumptions or generalisations about complication rates associated with the procedures.

What was considered important was that the women could describe distressing times with after-effects and complications but could still say it was a good decision and recommend this treatment to others. This illustrated that any complications they experienced were put into the context of their lives, which was much more important in the context of the study. Having decided upon a qualitative exploratory study, it seemed to contradict the theoretical framework to introduce pre-conceived ideas into the research setting.

The participants did talk about treatment complications, extended hospital admissions, repeated surgical procedures, pain, numbness, fatigue, swelling, and skin reactions, but what was more interesting was how they contextualised these into their lives and what this actually meant, which was not as significant as the individual symptoms described. Throughout the analysis presented in section 5.5, the level of treatment complications are discussed. These women were certainly not free from problems and had significantly difficult times. The overall positive finding does not relate to the absence of complications but rather to the reflection on the experience as a whole and what it means.

The participants did mention persistent problems with their treatment and these will be expanded on below.

All 14 women made a comment about the radiotherapy specifically. Participants 4,5,6,12,11 all said the radiotherapy was 'ok' or made no specific change that they could identify as due to the radiotherapy. However, all but participants 2, 4 and 12 mentioned radiotherapy 'burn'. This could be quite severe for example:

'…I burn on the under the arm...I had all this, like this, even I can't walk, I can't sleep. If I sleep I put jelly here. It's so terrible…' (F1:P3:L929) and this persists *'…But this side is very weak, painful, I can't move like this, you know. It's very painful…'* (L18). But for this woman looking back *'…Compared to before, when there was nothing wrong with my body at all, now I just, I love it…'* (L449).

This clearly shows how the woman has put this behind her '*I'd forgotten about the burning through radio, because for the first few weeks it's kind of fine...You know, and then it suddenly all happens...'* (F2:P7:L988) but she also says *'…But you're a year behind me and mine have totally gone now...Yes totally, totally gone…'* (L950). However, she also alludes to it not totally going *'…But it's still slightly different...it's like with bad sunburn….'* (L935).

Other random examples of conflicting statements and significant problems can be seen from the statements below:

'…I did have a bad reaction to the radiotherapy as well. It was really difficult…' (F1:P1:L974) says this together with this as a lasting problem *'…and the thing they've accounted it to is possibly the radiotherapy has damaged it, that area there...'* (L977). But the overall *'…yes I had a crap time, but I would still recommend it. It is an extraordinary thing…'* (L432)

'…You know then I had the radiotherapy. I not burnt from here, burnt from here. Yes, here, down the breast is very, very painful. It's big, you know...' (F1:P3:L927).

And there were conflicting statements such as where the participant starts stating that it was all OK but then adds that she is not back to normal:

'…Yes I've got back to normal feeling everything now. But this side is very weak, painful, I can't move like this, you know. It's very painful...' (F1:P3:L18).

'…But with radiotherapy after that, I had, you know, the whole reconstruction was meant to be nice and new. It all went from dark to black and swollen and really red and angry...' (F3:P10:L614) And also that this was lucky *'…I was one of the lucky ones and I'm getting off lightly having just radiotherapy...'* (L1000).

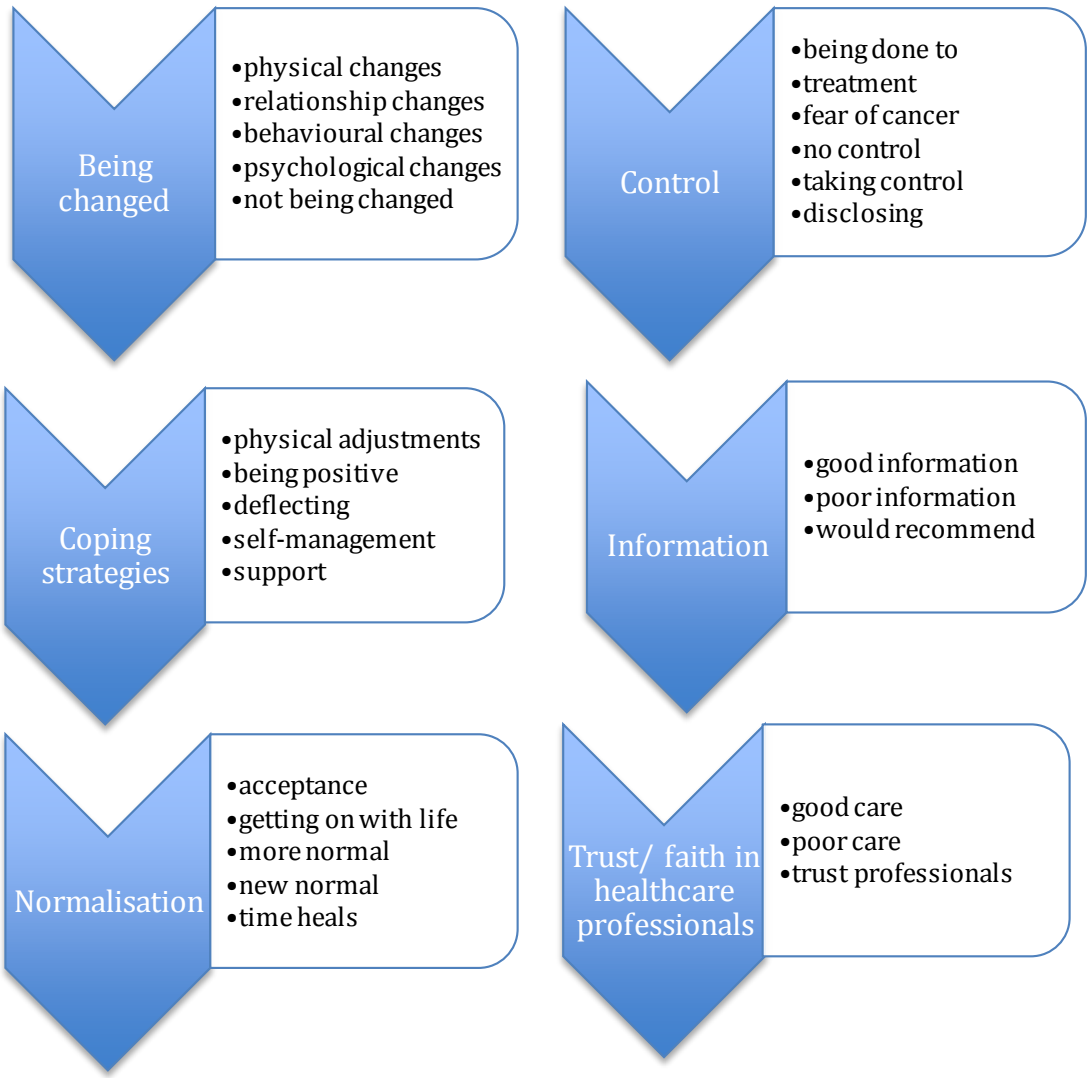
'…Sometimes after radiotherapy, sometimes it's just breast pain, not all of the time, but sometimes like a, like putting some knife…' (F3:P13:L1004), however, what is more important is being the same person *'…Yes. It's still the same woman...'* (L757).

These comments are illustrative that there were problems within the sample but they were put into perspective and accepted in context of their overall experience.

5.5 Identified additional themes

In addition to the effect of radiotherapy on the reconstruction, analysis revealed six discrete themes that were discussed at length during the groups and were of apparent importance to the women: *Being changed, Control, Coping strategies, Information, Normalisation*, and *Trust and faith in healthcare professionals*, and 27 sub-themes were identified across 1046 verbatim statements. Although these themes and their associated sub-themes were often overlapping and interconnected, the characteristics of, and differences between, the themes and concepts were identified. The themes and sub-themes are displayed in Figure 5.3.

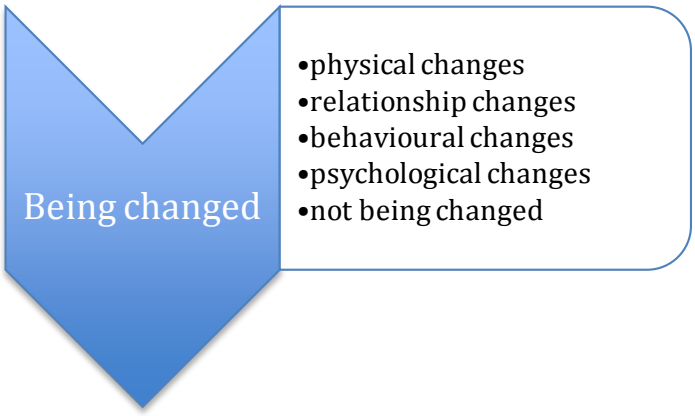
Figure 5.3 Identified themes and associated sub-themes



5.6 Theme: Being changed

There were 303 statements representing the theme of *Being changed* by the experience of having radiotherapy after DIEP or TRAM breast reconstruction (Figure 5.4). These were the lasting effects of having cancer and cancer treatment, and included physical changes (specifically changes in the breast, numbness, tiredness and persistent discomfort), psychological changes, behavioural changes (including the need for medication), relationship changes, and the way some things had not been changed as a result of the experience.

Figure 5.4 Theme of Being changed with associated sub-themes



5.6.1 Sub-theme: physical changes

The 'physical changes' that the participants discussed related to differences in the breast (such as size, lumpiness, hardness), persistent pain or soreness, numbness, tiredness, persistent pain, the way their bodies looked, the associated menopause, dry itchy skin, poor sleeping, and general wellness.

5.6.1.1 Relating to the breast

Participants in all focus groups discussed the lasting differences in the look and feel of the breast. The women comment on the breast feeling alien or unreal, one participant relates to the reconstruction as '*the breast*' and not '*my breast*' (F2:P9:L169). Other examples include:

'… You didn't say to me that "this breast won't feel like your breast"...' (F2:P9:L589)

There were a number of comments shared within the focus groups about the effects of radiotherapy on the breast, especially relating to swelling or the skin pigmentation that occurs during treatment:

'… And it took a long while for it to settle down before they did another surgery to adjust it. …Because of the swelling …' (F3:P11:L248)

'… and the skin, the colour of the skin changed ...' (F2:P8:L936) and *'… Yes it was all darker, yes … still darker … it fades but it's still not as …'* (F2:P10:L938).

Participants likened the skin changes to being in the sun, or sunburn, for example:

'… Like, it's like with bad sunburn. I mean that's exactly what it is effectively isn't it …' (F2:P7:L935)

'… all the tissue is still burnt and it's not very comfortable …' (F3:P11:L268).

There were also comments about the hardness, lumpiness or heaviness of the breast and breast tissue, this may or may not be related to the effects of radiotherapy or surgery alone, for example:

'… the thing is the tissue becoming very hard. Like last time when I went to mammogram, I said, 'No I can't, I don't know which part is lump or which one is not …' (F3:P14:L1013)

'… this breast … it's still bumpy, bumpy. It's just strange …' (F2:P9:L177)

'… it has hardened a little bit over the years after radiotherapy. It was very soft before …' (F1:P1:L772).

One participant discussed the radiotherapy effect on the reconstruction when she described the comments of her plastic surgeon, suggesting that he was not pleased with the cosmetic results post combination of treatment, but she did not mention her own view:

'… But my consultant was a bit disappointed at the, you know, having Mr xx doing the plastic surgery, whatever he had done and looking at the

results, didn't match up so well after having radiotherapy. And the effects of radiotherapy on your breast. I don't think he was too pleased with what he had envisaged it would look like …' (F2:P10:L878).

Seven participants within all three focus groups discussed the breast size following reconstruction. There were some associated comments relating to wearing a bra, mainly that the women had needed to buy a larger one:

'… When I had operation, it was a little bit bigger. But he said, the doctor said it's big better than the small so I can take a bit … – yes just the bra …' (F3:P14:L240)

'… Well I've had, my bra size has changed because I've got big breasts now...' (F1:P1:L350)

'… So mine got bigger, which was a good thing. But ... but it meant my bras didn't fit any more …' (F2:P7:L863).

There was also associated asymmetry of the breasts post reconstruction:

'… One breast is a little, the reconstruction is a little bit bigger than the other one. This one droops …' (F1:P5:L112).

Three women described undergoing further surgery to obtain better symmetry; one made no comment about the results of the further operation, one said it resulted in her having smaller breasts which to her was '*a good thing*' (F1:P2:L489); while one made no comment about the resultant size of her breasts, rather that the operation on the contralateral breast occurred because there was *'…a hell of a lot of difference…*' (F1:P1:L826). There seemed to be general consensus relating to differences in size of the breasts (smaller or larger), which was that the women were happier with their post-surgery size. However, one participant described her disappointment with her breasts:

'… I saw these pictures of nice firm breasts, for want of a better word. But my breast doesn't look that way...' (F2:P8:L869).

Another significant feature about the breasts *Being changed* concerned the nipple. This area was generally discussed in relation to the theme of *Control* and will be discussed in section 5.7.5

5.6.1.2 Relating to numbness

All but two participants (P1, P13) commented on experiencing numbness. There were general comments, statements that related to its temporary or permanent nature and, although there was one comment relating to the DIEP flap donor site, in the main they concerned numbness in the arm and the breast. Some of the women appeared quite matter of fact and not unduly distressed:

'… I can feel that I'm touching my breast but not like with this one …' (F2:P7:L145)

'… I didn't realise there would be like numbness as in I would not feel... It just feels very weird …' (F2:P9:L170) *'… but it's not, it doesn't stop you from, it doesn't stop me in terms of my movement. It's just realising that, wow, this sometimes feels really weird …'* (F2:P9:L180).

Three participants (P7, P8, P10) described the numbness stopping them finding the origin of an itch, and one described problems using deodorant, not being confident about applying it:

'… Well try doing that when you can't feel with a roll on! ...' (F2:P7:L132).

Four participants described the numbness as temporary and the experience getting better, with the *'pins and needles'* (F1:P5:L88) wearing off in time. Participant four felt the numbness was a positive effect of the operation and a reason for not feeling pain at the time of surgery:

'… There is no pain in that respect, you know. Your stomach's numb, your breasts are numb. So nothing is an issue unless you accidentally knock or, you know, do something like that. But because it's all numb it was like, "I feel fine." …' (F1:P4:L106).

5.6.1.3 Relating to tiredness

Tiredness was a common thread of this sub-theme and discussed by 11 participants over all focus groups. A number of participants discussed being less able to achieve as much as before the cancer and its treatment, due to tiredness. One described the need for an afternoon nap, while another said she often repeatedly nodded off when staying up late chatting with friends, for example:

'… and I fall asleep, they'll go, "Leave her, she's having a power nap, she'll be back in half an hour." And sure enough in half an hour I kind of go, "Hello what did I miss?" And then an hour later I'll do it again …' (F2:F7:L348)

'… I find I tire quickly as opposed to when I didn't have cancer, before the operation. Yes, my stamina is not as it used to be …' (F2:P10:L209)

'… But sometimes I feel like I'm not like before. I'm getting tired quickly...' (F3:P14:L278).

Some participants illustrate the frustration associated with this and its impact on their employed work, studying, chores such as housework, shopping and social activities, while others appeared relaxed, dismissing a nap on the sofa as *'fine*' (F2:F7:L348).

5.6.1.4 Persistent pain

Thirteen of the participants reported persistent discomfort. This was described as aches and pains in the joints, likely to be related to side effects of endocrine treatment, or pain in the breast, donor site and arm. Some participants experienced pain undertaking certain activities, for example,

when exercising the arm (F1:P2:L10), when painting toe nails (F1:P1:L2), when writing on the board (teaching) for a long time (F1:P4:L24), or when carrying too much (F1:P5:L30, F1:P6:L121, F3:P14:L56). A number reported pain near the donor site; one mentioning she had tenderness as the elastic on her undergarments rubs and sometimes when moving in bed she, *'… sort of feel(s) the site pulling slightly …'* (F1:P5:L67).

It is interesting that a surgeon decided radiotherapy was responsible for the pain a participant experienced:

'… he said it is because of your radiotherapy, all the tissue is still burnt …' (F3:P11:L268).

However, when another participant described *'stabbing pains'* post DIEP reconstruction, it could be seen that these were identified prior to the radiotherapy delivery (F2:P10:L616). Pain and discomfort were also reported to affect sleeping. Three of the women shared they could not sleep on their side for too long (F3:P13:L223, F3:P14:L237, F3:P11:L234) and one mentioned sleeping on her stomach was uncomfortable (F3:P12:L251).

5.6.1.5 Other physical changes

Being changed physically also encompassed threads of comments relating to the abdominal scar, chemotherapy-associated weight gain, swelling of the arm and a new umbilicus. Seven participants in all focus groups mentioned the abdominal scar, including one woman whose small son was frightened when it showed on holiday and she wished she had the finances to have plastic surgery despite feeling the scar was *'very good'*. (F3:P14:L880). Two participants mentioned the new umbilicus, but this seemed to be an accepted effect of treatment, for example:

'… But now I don't really notice it. But it just, now it's just there...' (F2:P9:L874).

Weight gain was also alluded to: some being pleased to have gained weight to help the surgery; others discussing the ensuing weight loss, for example:

'… obviously it helped that I gained weight doing chemo because then they had enough tissue to use …' (F1:P1:L647).

'… now I lose about eight kilos, lose my weight …' (F2:P8:L868).

Participants described the discomfort associated with the menopausal hot flushes induced by the treatment, especially around poor sleeping. One woman explained her ritual of using a fan with the windows open at night, even when in cold weather, as being, *'not really fair on'* her husband (F3:P11:L822) and another described how not sleeping had compromised her work:

'… And there have been mornings when I've woken up and I just physically haven't been able to go to work ... And so my kind of, my attendance has suffered definitely. But there are days when I know that if I go in, I will be next to useless to them, you know … And I have found that quite hard because I've always been someone that's, you know, you go in no matter what is wrong with you. And at first I did that and then it just got worse...' (F1:P6:L350).

5.6.2 Sub-theme: relationship changes

Eleven women mentioned changing relationships. The women talked about family, friends and intimate relationships with partners and husbands. Some relationships had improved but, for others, the experience had a negative effect. Participant 1 spoke of anger from her sister that culminated in a relationship breakdown because of the improved relationship between the participant and other siblings, and another described how her sister now experiences panic attacks as a result of the experience of supporting her through treatment.

A number of participants discussed issues they had experienced with their children, which, on the whole, were positive. After discussing the situation with their children, they seemed to find resilience, and a way to live through the treatment with a level of understanding and a sense of needing to be more help practically around the house with chores, for example:

'… I said to my husband that after surgery … "Bring them along because I want them to see what I'm going through ... I want them to pull their weight around the house!"…' (F2:P9:L376).

Generally friends and family had been supportive, although participants discussed fear of being seen differently, even pitied:

'… Not I don't like feel the … (pity?) ... Yes. Yes, I don't like this feeling. And I like to see my friend arrive and very proactive and with high energy. And I wasn't, but I don't like to see me like ill …' (F2:P8:L571)

'… I find it's not something I like to discuss with my friends because I don't like them feeling pity. I hate them looking at me like they're saying "Oh poor xxx" … (F2:P7:L386).

This concern about being seen as an object of pity was also expressed in relation to healthcare professionals when a district nurse said *'… it must be awful for you …'* (F3:P12:L719) the participants felt as though '… *she was looking at me like I was some poor kicked puppy or something …'* (F3:P12:L722).

Another stated that support came, but not necessarily from the people from whom one assumed it would:

'... It's just weird how people that you expect to be there for you and they sometimes are not. But the people you don't expect are there all the time …' (F1:P5:L340).

This participant also added that, since her breast cancer diagnosis, she had become much closer to her brother, with him telephoning her the day after, attending appointments with her and that they remain closer:

'… But it is, it's like how relationships can change. I mean I never thought I'd be as close to my brother X that I am now … But it is amazing. Like the least person you think that you will be close to and have that bond with …' (F1:P5:L337).

Sexual relationships and intimacy were discussed in all focus groups. Most comments related to relationships that had commenced prior to the surgery and alterations and changes in feelings since. There were some comments about new relationships; one woman was scared and avoided sex with her new partner in case he *'doesn't like'* her new breast (F3:P14:L817). She stated that, although she is three years post-treatment and he is supportive of her, she still cannot further the physical side of the relationship which makes her '*sometimes (I) feel very sad'* (F:3:P14:L808). A participant who was single said that she could not imagine showing her body (or breasts) to a new partner, and was *'very, very conscious of myself'* (F3:P11:L811). Another stated that, although she was relaxed with the reconstruction she was scared of showing her breast to someone intimately unless she found the right person who respects the fact that it does not matter:

'… you know, you'll find someone who respects that …' (F1:P1:L781).

One participant's ex-husband was a '*breast guy'* and she thought he would have avoided that breast, although she added that it would have been *'okay'* (F2:P7:L789). She described having new relationships since the operation and always informed partners about the treatment. Although there have been no issues, she added her attitude to anyone who had a problem would be:

'… Well if you can't handle it, I'm not going to cover it up...' (F2:P7:L789).

She also said that these have been more casual relationships but if faced with a serious relationship or someone she '*really liked*' then she would wear something to cover her breasts the first few times they were intimate.

Those who were married, on the whole, had no problem with intimacy and, while some said it took time due to wounds and feeling sore, another shared that, as a couple, they were her eager for her discharge from hospital in order to resume their physical relationship (F2:P9:L800). Two participants shared that the husband ignored the new reconstruction breast, with one commenting that it had been his '*favourite*' breast and now he tended to move his hand to another part of her body relatively quickly, although he did interact with it (F2:P9:L803). One stated the intimate relationship had changed, that it had not ceased, rather altered and not necessarily in a detrimental way (F1:P4:L785). How the participants viewed themselves with partners was mentioned, for example:

'… I think if anybody has any hang-ups, it's really me...' (F2:P9:L800)

'… don't like being naked in front of my husband. … I am embarrassed...' (F2:P8:L795).

5.6.3 Sub-theme: behaviour changes

The participants commented on having adopted different lifestyles or behaviours since their treatment. Participant 1 admitted she was a workaholic prior to the diagnosis but altered her career pathway radically to become a life coach, interested in nutrition and her body, and reduced stress in her life. Only one participant mentioned different behaviour related to reducing the risk of lymphoedema and that she is mindful of carrying heavy items with her affected side (F2:P7:L138). Although others mentioned not being able to carry heavy items, for example:

'… I can't carry heavy things in my left hand …' (F3:P14:L245).

Taking or managing medication effects was a lifestyle change discussed within all three focus groups and by six participants. Comments generally related to the physical side effects of the endocrine medication they were taking with experiences referring to joint pain, hot flushes, weight gain, tiredness and disinterest sexually. There were no comments regarding not taking medication or non-compliance in any way. In fact, one woman said she would not stop taking anti-oestrogens *'… without speaking to my oncologist …'* (F1:P1:L428), despite having reached the optimal length of time for taking the treatment. One participant described having to break up her workday commute in order to combat hot flushes and anxiety, which she attributed to the medication:

'… I had to get off the train in between stations because I was just too hot or anxiety and it did affect me that way. Not into work and, but yes, just travelling …' (F3:P11:L394)

There were other small changes that the women made to their lives, such as cancelling a fencing course as it was no longer appropriate to use the arm so much (F1:P6:L346), or changing the way they dressed. One woman suggested that when she wore a dress, the size difference of her breasts is apparent (F1:P3:L1053), whereas another stated that she had not changed her choice of clothes, although may be a little careful where the clothes sit around the waist and donor site (F2:P7:L38). In the main, comments relating to clothing were about bras and the use of non-wired ones. Although most had returned to their wired bra styles of old, some were still unable to wear wired bras or wore bras with more covering or padding when compared to the styles previously worn, for example:

'… I used to always wear an underwired bra and I can't do that now because it's too uncomfortable …' (F3:P12:L58)

'... Yes we have to buy a bra with more cover like in here and here, and some clothes to – whereas before I used to wear very open...' (F3:P14:L54).

Participant 9 used to hate wearing a bra at home in the evening but described now using one on in order to combat the asymmetry she feels (F2:P9:L48). One participant detailed she had to buy a new dress and bra because her size had changed (F2:P8:L44), and one disclosed that she can no longer wear such tight t-shirts (F3:P11:L51). However, these changes were also recognised as not significant, for example:

'… I'm not that bothered. But it slightly alters that kind of choice of the clothes you wear a little bit...' (F2:P7:L41)

'… I just feel it doesn't look right, but it's okay, you know. It doesn't bother me that much that I feel like that …' (F3:P11:L51).

5.6.4 Sub-theme: psychological changes

Comments around the psychological effects of the changes concern how these changes made the participants feel and how the difference they felt affected the more social and interactive aspects of their lives. Participants shared discussion around accepting that things would not be the same as before:

'… And you keep believing that you can keep doing the things you used to do, and you really can't...' (F2:P9:L193)

'… because life isn't going to be the same after this … And it had to be seen that, you know, I just wanted to drill home to them that mummy's not super mum anymore...' (F2:P10:L622)

'… And I think, I think you raise a really good point that there are some things that you will have pretty much for the rest of your life...' (F2:P7:L946).

The women talked about things feeling very different, including the breast feeling different and not their own, for example:

'… It feels like to me like I have an attachment on my body...' (F3:P9:L171).

Participant 11 mentioned that although her breast had a different look to it, she did not feel self-conscious about it, but she did add that she would no longer walk around topless at her gym (F3:P11:L882). Other comments referred to Participant 12's fear that, although her arm was not swollen, she was at risk of lymphoedema (F3:P12:L233), and how being different feels. One participant stated how difficult it was to get used to when she looks at herself and the reconstructed breast did not feel like her, rather an 'attachment' on her body; 'something stuck' to her chest. She added:

'… I feel like I've been chopped in half. I feel like I've been stuck together. Am I supposed to feel like that? Am I supposed to feel like when I stretch, it's almost as if I'm going to be pulling myself apart? ...' (F2:P9:L174).

There were many positive comments about being changed, and some women stated they were calmer. One woman had found a stronger faith and felt more mature, interacting with people in a more helpful manner (F3:P14:L742); another had reassessed her life, which resulted in her giving up her job and studying:

'… And this really pulled me out of that situation and made me reassess my life and now I have given up my job and I am studying to be a life coach ... Yes, very big change …' (F1:P2:L296). Later she added *'… but you know what, I love my body now...'* (F1:P2:L832).

One woman, however, felt guilty when she was required to attend hospital appointments within work time as she had just returned to employment. Another spoke of the different parts of her life, having spent much of her time undressed while having treatment and appointments:

'…You spend such a lot of time topless when you're going through all the – it is really bizarre, when you're sat there with, you know, naked from the

waist up, talking about books or something with a radiotherapy nurse, that's really weird trying to get your head around that...' (F3:P12:L668).

5.6.5 Sub-theme: not being changed

The use of focus groups enabled a discussion to develop where participants could express different perspectives and 12 of the participants described aspects of not being changed. Many reported no ill effects specifically regarding this combination of treatment. One described working part-time through the treatment with no detrimental issues except some tiredness (F3:P14:L1005). Four of the participants (P4:P5:P6:P7) categorically said 'no' when asked if radiotherapy had any effect on their reconstruction and other examples included:

'*…I didn't burn, I didn't feel anything … Even I didn't change colour...*' (F1:P2:L925)

'*… but I don't think the radio changed that at all …'* (F2:P7:L990).

Seven of the participants across all focus groups talked about carrying on 'as before', socially and actively they continued doing the same as they had previously:

'*… But activity, no … I've kept on doing the things I did before. …'* (F1:P5:L117)

'*…Yes, but before operation the same, nothing not changing. Yes. It's still the same woman...*' (F3:P13:L757)

'*… No I'm back swimming, go to the gym. I don't find anything else particularly that I can't do, any more so than I didn't do in the first place...'* (F1:P4:L314).

Being able to carry on as before was specifically associated with having the reconstruction:

'… that's the great thing about having the reconstruction is that you don't, you can, it's part of you, so you just do everything you did before …' (F2:P10:L389)

Five women commented on issues of clothing and all appeared to have no residual issues post treatment, for example:

'… yes still wearing the same bras. I still wear underwired bras, I don't, I haven't had any issue at all really...' (F2:P9:L46)

'… I don't think any difference particularly from before. Surgery was great. You know, I still wear clothes the same …' (F1:P4:L21)

5.6.6 Summary of theme: Being changed

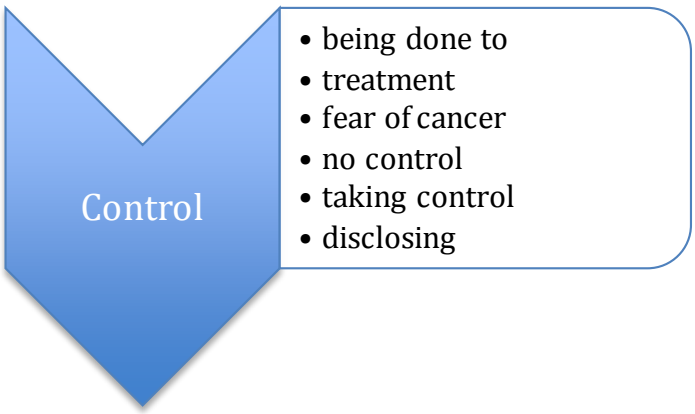
Participants discussed *Being change*d from different viewpoints: the physical, psychological, social and behavioural effects of the treatment. Physical aspects related to the reconstructed breast on the whole, although there were a few comments related to the donor site. Changes in the shape, size, weight and texture of the breast were all reported, but not necessarily as having a negative impact. Numbness, tiredness and persistent pain were enduring physical effects, but generally did not appear to have major impact or implications. Relationships changed for these women, but these were mostly supportive, even though family and friends often felt helpless. Intimacy was discussed and most had resumed activity with previous partners or found new ones. The effects of radiotherapy on the breast were held within this theme and the comments appeared to be neutral towards this combination of treatment, once the burning at the time of the treatment settled. This theme also housed comments about wearing different clothes, feeling different, even calmer, post this episode of treatment. The comments regarding endocrine medication described side effects that seemed to be accepted as part of 'the deal' of being treated. Perhaps the most important finding within this theme was that the women thought the radiotherapy had little or no effect on their breast reconstruction. Otherwise the women

appeared quite resilient, many describing they felt as they did before and wore the same clothes as before.

5.7 Theme: Control

There were 298 statements associated with the theme *Control*, which includes times when the participants felt like they had no control or when they actively took control in a clinical or social setting (Figure 5.5). Control varied through the experience, at the time of treatment and the lasting effects. Taking control was sometimes alluded to as a coping strategy, however, specific descriptions of regaining control are described within this theme.

Figure 5.5 Theme of Control with associated sub-themes



5.7.1 Sub-theme: being done to

Loss of control was evident in descriptions of 'being done to' or 'being told' by healthcare professionals and was reflected in the language of 'they did' or 'they said'. This sub-theme was commented on by thirteen participants and included times of extreme vulnerability such as in the post-operative period, for example:

'… And I was really kind of leaning over and he was like, "You need to stand up straight," and I couldn't, I couldn't stand straight. …' (F1:P2:L72)

'… I don't like on the second day they come and they say, "Oh come and sit on the chair." That's so terrible, I can't do that the second day …' (F1:P3:L86)

Not being in control of the cancer and treatment was often referred to. Participants described how doctors diagnosed the cancer and decided the treatment, for example:

'… because everything happens so quickly, like they diagnose it and then they do all these different tests. And you just kind of get on with it …' (F3:P11:L690)

'… It got really swollen after my radiotherapy. This side got really swollen, so they did – again they did a surgery to sort of cut down the swelling …' (F3:P11:L219).

Many of these comments related to the type of breast operation and reconstruction that was offered to the women. There were some comments on why implant-based reconstructions would not be appropriate in their individual cases and also why a mastectomy was necessary in the first place. These were mainly down to clinical judgment and medical expertise. A couple of comments referred to the doctor's response to the effects of having radiotherapy post-operatively, for example:

*'... and the thing they've accounted it to is possibly the radiotherapy has damaged it, that area there...' (*F1:P2:L977).

Two comments appear to illustrate that radiotherapy post reconstruction would not make any difference to the reconstruction:

'… I wasn't sure whether I should have … the reconstruction after, because potentially there was, potentially some damage to the tissue by having the radiotherapy. But then after more discussion and talking to my consultant … they strongly recommended doing it together …' (F3:P12:L663)

'... well my surgeon had actually written quite a few papers on the disadvantages of doing radiotherapy after surgery … But he said, "I wrote that a long time ago, and I truly believe now, with this type of surgery, it's going to be different"…' (FI:P2:L430).

'Being done to' was not always seen as a negative experience, for example:

'… I felt I had, to be honest in some ways I felt like I had too much choice. I didn't want to make the choices. I wanted someone to just tell me …' (F2:P9:L628).

'… when they make that decision it's a lot easier than you having to decide, "Do I have implants, do I have this?" If they say you can't, then you're like, "Okay, that's fine." …' (F1:P2:L402).

5.7.2 Sub-theme: treatment

'Treatment' was an important factor in control and was discussed in relation to having no control on the drains, side effects, hair loss, radiotherapy burning and pain. Participants described the drains as a nuisance, hurting if pulled or stressful if having them at home, and the women detailed both immediate post-operative effects of treatment, such as surgical pain and longer-term effects such as arm pain. There was one comment which described thoughts of attending the cancer support centre whilst an inpatient just after the operation:

'… I kept thinking, "… I must come to XXX [name]," but you're in your gown and you've got all your drips and you don't really want to go wandering around in public. And you also think if women have come here to find out and then I turn up bald, covered in tubes in a hospital gown, they're going to run for the hills! ...' (FI:P6:L344)

No control over hair loss caused by treatment was referred to. A number stated the hair loss was in '*handfuls*', which appears to have been unexpected, they describe it as awful and upsetting. One participant said that

she had no notion that the hair loss would be all over her body, and described being in the bath and noting her pubic hair was also coming out (F2:P9:L1041). Although these participants mentioned the hair loss they experienced, one also mentioned the effects that this had on what she felt she looked like:

'… You just look like an egg don't you? You wake up every morning and there's just this little egg shaped face …' (F2:P7:L1037).

Ten participants commented on radiotherapy burning, although it is noted that all the women in the room were nodding in agreement:

'… And the radiotherapy, sometimes the skin burn, it burned, oh yes. ... The cream and the gel pad, yes it was helpful … You're all nodding at that, I think that happened to all of us …' (F2:P7:L932:L33).

Many of the comments about no control of treatment effects appear to be associated to the immediate post-treatment phase, and so may not be relevant to answer the research question, which related to the time period from years one to five post completion of treatment. All of the treatments (surgery, chemotherapy and radiotherapy) were described as difficult, tough, big, or taking a long time by some of the participants. Six participants commented on their experiences being tough whilst having chemotherapy and these ranged from one describing she would prefer to die rather than have chemotherapy again (F3:14:L1046), to others saying it was awful and tough, to one participant stating that she did not think it was as bad as it was in the past as there is now the benefit of anti-nausea drugs (F2:P7:L1034). Two of the participants detailed their experiences of becoming neutropenic and being quite ill; one stated that her high temperature had continued for 11 days and that a healthcare professional said she had nearly died (F1:P6:L1026; F1:P2:L1022).

Radiotherapy fatigue was commented on, and this fatigue had stopped one of the participants from doing things for almost a year:

'… I suffered from so much fatigue from the radiotherapy. That lasted almost a year. That stopped me doing things …' (F1:P4:L982).

However, another stated the fatigue lasted only a couple of months (F3:P11:L969). One participant commented on the radiotherapy being tough because she was physically and mentally tired by this stage in the treatment trajectory and that the treatment itself felt quite impersonal:

'... because it goes on for so long, it's every day of the week. And I think you've gone through so much by then, mentally and physically. But the actual treatment is fine … but it does feel quite impersonal …' (F2:P7:L986).

Surgery was discussed in relation to the size of the operation. Many compared long operating times, up to twelve hours, and extreme weakness in the immediate post-operative period (F3:P11:L25). Other comments ranged from not wanting any additional surgery to even up the breast cosmetically (F2:P9:L585), to the surgery having been unpleasant and having little memory recall in relation to the first three post-operative days, which she thought was a good thing (F3:P12:L765). Participant 11 thought she had made the right decision by having an immediate reconstruction as she would not be sure if she would have opted for more additional surgery at a later date (F3:P11:L:681).

Two of the women reviewed their whole treatment experience, one saying it was horrid (F1:P5:L573), while the other said that she could look back and laugh now, and yet at the time the experience had been tough (F1:P6:L524). However, there were comments that the experience of chemotherapy and radiotherapy had not been too arduous, one stated her operation went well and that she had felt lucky, as she had not had any abdominal scar problems (F3:P11:L286).

5.7.3 Sub-theme: fear of cancer

'Fear of cancer' was expressed in some way by all the participants. This was described as not being able to escape the disease because of the media, the

fear of tests and the need to be treated quickly and thoroughly. Cancer awareness information was expressed as an unwelcome reminder of the disease:

'… I get a bit tired of all the cancer things in the paper. I know they've got to make people aware, but you sometimes think, "I've had enough. I've been through it, I just want to forget about it for a little while." …' (F1:P5:L903)

'… And then all of a sudden some will say something or read something in the paper. And all of a sudden that fear comes back again. …' (F1:P5:L906)

Others stated that although normally they continue their lives, that sometimes if they experience pain or another symptom, then they imagine it is the cancer back once more:

'... just every now and again I have a little wobble …' (F1:P5:L907)

One worried that if she returned to a stressful job it may result in the cancer coming back, while others detailed they were scared of the cancer returning, and that this thought was always (although mostly buried) at the back of their minds. Two participants commented that, after completion of treatment, the fact that there were no longer healthcare professionals around was worrying, and tests could be seen as both worrying and reassuring:

'… So every time we have a mammogram, it's a worry …' (F3:P11:L713)

'... I don't really think about it. And apart from probably a little way ahead of the mammogram, then it's on my mind. … And then it's a huge relief and then you forget about it …' (F3:P12:L912)

Seven felt they had no choice but to have cancer treatment and *'get rid of it'* (F1:P2:L441) and survive:

'… my first thought was always, "Just get it off" …' (F2:P9:L629) and *'… because it was something that if I wanted to survive, I had to get on and do it …'* (F3:P11:L696).

Some wanted to undergo treatment as soon as possible; Participant 2 even said she wanted it the day after her diagnosis (F1:P2:L442). Most seemed to have come to terms with the treatment and be content with its radical nature, for example:

'... And now I'm really glad that I had a mastectomy because I'm the kind of person who would be sitting there thinking, "What if there's a speck left in there?" So I'm just completely comfortable that was the right thing to do …' (F1:P2:L401).

5.7.4 Sub-theme: no control

'No control' specifically concerned descriptions of influences that felt external to the participants such as luck/fate, shock of diagnosis and feeling as if it was happening to someone else, like a bad dream:

'… Yes actually, yes it was like a dream and it's gone, a nightmare actually …' (F3:P14:L707)

'… it's like having a baby, you just go and then suddenly you think, "Oh my goodness, what's happened?"...' (F3:P12:L654)

Four participants described luck or fate playing a part in their experience, this ranged from being lucky to find expert healthcare professionals or only requiring surgery and radiotherapy, to being fated to have the disease:

'… But I kind of grew up thinking, "You know what, from all of the sisters, I might be the only one who might have it," and I did. … And when I

did have it, … I was kind of like prepared for it somehow, I don't know. But because I'd seen my mum going through it, it was like, you know …' (F3:P11:L741).

Shock at diagnosis was commented on by 10 participants. Only Participant 5 stated she suspected the lump in her breast was serious. A number of the participants described disbelief at the diagnosis, as they were not experiencing any pain or symptoms associated with such a diagnosis, for example:

'… You're kidding, you must have taken the wrong person's picture here. Nothing wrong etc. …' (F1:P4:L497).

Many described the surreal out of body nature of being diagnosed with cancer, especially Participant nine:

'… No, it's not really happening to me. Yes, it really is happening to you. It was just, just weird … That's what I can remember. I keep thinking of things like sometimes, you know when you see movies, when you can hear people, like freeze-frame and you can hear everybody is talking to you and you're just sitting there ... It just feels surreal and weird …' (F2:P9:L574).

5.7.5 Sub-theme: taking control

'Taking control' related to descriptions of where the participants were able to take control, sometimes over relatively small details, but these were obviously memorable and important to them. 'Taking control' of the chemotherapy-induced alopecia by actively cutting or shaving the hair was commented on by six participants, with five of them detailing shaving their heads either as a control mechanism or because it was too messy to find hair on the pillow or in the bath:

'… So I just shaved it off the minute that started happening, because obviously waking up with a pillow full of hair and the bath being full of hair was just- I put up with a week of that, and just got rid of it …' (F2:P7:L1033).

Participant 4 was the only one who commented on wearing a wig, and her dislike of them:

'… I wore a wig. I hated the wig, I would do anything, I wore scarves, I just don't like the wigs, really couldn't bear them …' (F1:P4:L474).

None of the other participants explained if they wore anything to cover their heads whilst they were shaven, or if they in fact walked about with their bald and shaven heads on show (except for the reference to not frightening others in the cancer support centre 5.7.2).

Being able to make decisions was commented on by five women. Many of these comments related to managing with post-operative drains, including not wanting to go home with them:

'… "Look you can go home but you'd have to go home with the drain." And I said, "Forget it then, I'd rather stay." …' (F1:P1:L409).

Other comments concerned additional, corrective surgery for cosmesis or on the contralateral breast that had been offered to the women, but they had elected not to have. One participant had been offered radiotherapy as part of a trial and felt in control of the decision to participate even though she would then be randomised (F1:P4:L889). Other decisions included nipple reconstructions or tattooing; many deciding not to have these done because they would not be topless in public, were in a stable relationship, had had enough surgery, or it would simply not make that much difference:

'… And I could have had my nipple tattooed. Do you know what, I just thought it's never going to look like a normal breast because I've got this socking great circle of scar …' (F2:P7:L550).

However, there was also recognition that each woman is an individual and responds to control or lack of control in an individual way based upon circumstances. This included the way participants may share the experience with other individuals faced with the same treatment-decision. One details that social factors would be relevant as if one had young children, or a lack of support, then this extended recovery phase of eight weeks may not be suitable.

5.7.6 Sub-theme: disclosing

'Disclosing', or choosing whom to tell, was an important feature of maintaining control and was mentioned by almost all of the participants at some point. There were also different levels at which the participants disclosed and maintained control of their own story with friends and family in a way that they could not within the healthcare system. There was a range in the level of detail that participants chose to disclose: some provided bare facts to family or friends, others gave more information even showing their reconstruction to work colleagues, for example:

'… I keep it like to myself and my family, I didn't let anyone to know in my community …' (F3:P14:L809) and *'… I showed my work colleagues …'* (F1:P4:L849).

'Disclosing' also included discussions with new partners:

'… You know … that's the way it's going to be. So you might as well know now, other than me kind of flounce around in a little negligee thing and pretend that nothing is lurking underneath for you to find out later …' (F2:P7:L793)

Hiding hair loss as a way of maintaining control was commented on, as was the control of who to tell associated with 'looking normal'. Having an immediate reconstruction helped some of the women to 'look normal' and not have to disclose any difference:

'… Yes it's nice and it's, I have breast, I am normally yes like look normal, yes I'm very happy …' (F2:P7:L555) and *'… I was just so thrilled to be leaving, as far as anyone else knew, just like a regular person …'* (F2:P7:L539).

Because of this, one participant described the procedure '*a genius-like operation*' (F3:P14:L699).

5.7.7 Summary of theme: Control

Control covered issues relating to having no control, but also actively taking control. No control was expressed in relation to 'being done to' within the process of healthcare and having no control over the disease process, including the shock of a cancer diagnosis and the desire to commence treatment. Making decisions could be difficult because the women often felt as though the medical team had the expertise to decide and deliver treatments, and that they were observers in their care as though it were happening to someone else. This 'other person' could be seen by others as an object of pity. This feeling of no control was compounded by the effects of the extensive and often difficult treatment, such as soreness from the radiotherapy, hair loss and pain, but most of this was in the short term at the time of treatment. However, the fear of cancer returning was still present, especially at times of follow-up and tests.

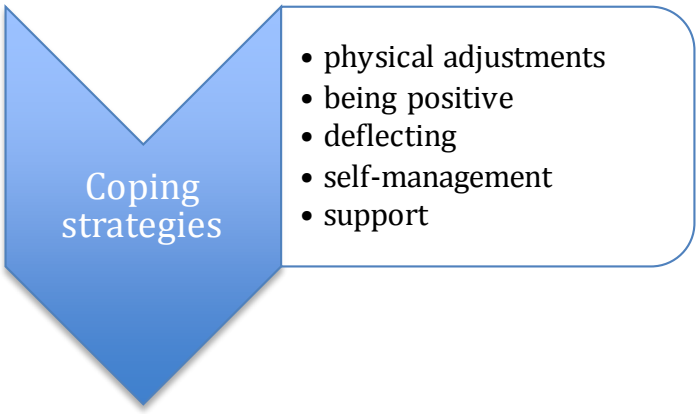
The women also talked of taking control over aspects of the experience wherever possible, such as in choosing whom to disclose to, especially in relation to the treatments, allowing participants to appear normal. Taking control over treatment effects included shaving heads to stop the distressing process of hair loss, not being discharged with post-operative drains, not wanting additional, more cosmetic surgery, nipple reconstruction or tattoo.

5.8 Theme: Coping strategies

There were 158 statements relating to the theme of *Coping strategies*. Coping strategies could also be seen as part of regaining and maintaining control, but this theme concentrates on specific techniques the women used,

such as adjusting to physical changes, having a positive attitude, deflecting from cancer and treatment, self-management, and the giving and receiving of support (Figure 5.6). Participants also spoke of ways they were becoming fitter or healthier to cope with the disease and avoid recurrence.

Figure 5.6 Theme of Coping strategies with associated sub-themes



5.8.1 Sub-theme: physical adjustments

Adjusting to physical changes was discussed by all participants and included aspects of adjusting to post-operative drains, fatigue and pain. Apart from managing post-operative drains, most strategies concerned the longer-term effects of treatment, how they coped with *Being changed*.

There were two comments describing adjusting to pain in the arm by not carrying heavy loads (F1:P6:L122, F3:P15:L57), while other pains were managed by waiting and breathing until the pain stops (F1:P1:L3) or finding a way to hold oneself when the pain strikes (F3:P10:L204). Comments that related to adjusting to fatigue described still having to have an afternoon nap on occasion, and one participant detailed alteration in her studying behaviour, for example:

'… But I still do sometimes feel more tired and I'll have to have a little afternoon nap if I can …' (F1:P6:L130)

'… I had to make those kind of changes in terms of just really making sure that I studied when I'm supposed to study and not try and push it to the limit …' (F2:P9:L198).

Other adjustments to physical changes were described. These mainly related to clothing, with some describing a temporary change in style of underwear; to a sports bra and large knickers in order that wounds and scars were not irritated. Others spoke of more permanent adjustments in clothing as described in 5.6.3. One comment related to the small tattoo left after radiotherapy and being careful with necklines when shopping for clothes due to people asking what the mark is (F2:P7:L40). But adjusting to physical changes was just something that needed to be done:

'… it just takes its toll on you and you just have to … take things ... easy …' (F2:P9:L194).

5.8.2 Sub-theme: being positive

Participants within all three focus groups described 'being positive' or 'being strong' as part of coping with their experience. This also included others being positive, offering support not sympathy. 'Being positive' helped, but it did not seem they were masking their own feelings in order to be positive, rather that they had positive ideas and thoughts about their treatment and its effects. 'Being positive' included comments from eight participants that related to actively 'seeing the positive' in the situation they found themselves. This included, using one's own tissue for the reconstruction, having put on weight during neo-adjuvant chemotherapy (as it resulted in more tissue being available for the reconstruction), and getting the same operative results as a 'tummy tuck' because of the reconstructive technique. One participant said having received radiotherapy to the armpit meant her underarm hair no longer grew, which was a bonus (F3:P13:L254). There were also comments that reflected on the positive of having the mastectomy and reconstruction performed at the same time, for example:

'… I think the operations are both so huge anyway, it's like twice the amount of recovery and having gone through it once, the thought of again would be really unpleasant … and it just would be too much …' (F3:P12:L670).

There were comments that related to the order of the treatment modalities the women experienced and how this, in retrospect, was best for them. This included having chemotherapy first when they were at their strongest:

'… I think if I was to have radiotherapy first and then go through the whole process of chemo, it would have just been too much …' (F3:P11:L261).

Participant 7 saw the positive when she was informed of activities she would not be able to fulfil post-operatively:

'… you will have a massive wound, you will take eight weeks to recover, you know, you won't be able to do the hoovering (Oh what a shame!) or the shopping (Oh what a shame!) …' (F2:P7:L548).

The participant who changed work vocation described how she felt the cancer experience *'… opens your eyes …'* and made her think about what she should do and slowing down work-wise was one of them (F3:P11:L751). Another participant stated the experience and the support shown by her family and friends had resulted in a *'… life affirming …'* experience (F3:P12:L745).

5.8.3 Sub-theme: deflecting

'Deflecting' away from the experience came in many forms. This included deflecting blame from treatment, forgetting or putting things to the back of the mind, justifying poor experience, making the unusual ordinary, working towards or away from milestones, privacy, using humour and considering things that could be worse.

Five participants deflected blame for things such as wound healing, fatigue and reaction to radiotherapy with other causes namely psoriasis, increasing age and ethnic background, for example:

'… I don't think, "Oh I'm tired because I've had radiotherapy six months ago." … I think that's finished and done and I'm just tired because I'm getting older and doing too much …' (F1:P4:L108).

One participant described forgetting just how difficult things had been with the burning effects of the radiotherapy and the change in skin colour (F2:P7:L558:L561). Participants also described what they imagined to be a necessary part of the process, a justification for what had happened. One participant attributed her cancer to the fact she was so stressed prior to its diagnosis (F1:P1:L421), others described feeling hot and uncomfortable post-operatively as a *'normal'* (F3:P12:L275)*, '… necessary process …'* (F3:P13:L276), and the lasting effects of the abdominal wound pulling as just part of *'… such a big operation …'* (F3:P12:L288).

Participants also described some of the extraordinary experiences using ordinary language such as comparing the post-operative drains to shopping bags (F1:P5:L34), comparing the operation to a *'car accident'* (F2:P9:L184) and referring to the operation as '*dinner party conversation*' (F1:P4:L425).

Milestones were seen as an important part of coping, discussed mainly within the context of getting through one treatment and moving on to the next. The treatments were the milestones or hurdles and the process was completed once the nipple tattooing had been performed, for example:

'… but as soon as you'd gone over half way, then that was a big hurdle …' (F3:P12:L711) and *'… the last thing, the tattooing …'* (F3:P11:L259).

One participant described having had her own room to recover in post-operatively, due to the fact she had her operation within the private sector, as helping her to cope (F1:P1:L408).

Many of the participants also used humour to lighten the seriousness of the experience. There were references to being on page three of the Sun newspaper (F3:P14:L730), laughing about putting cotton in the bra to even up post-operative asymmetry (F3:P13:L656), not having nipples to show in the cold weather (F1:P4:L324), and having to shave under the arm again after treatment finished (F3:P13:L254). One participant even described this as a coping mechanism:

'… so I joke about it … So, you know, and maybe that's my coping mechanism …' (F1:P4:L324).

Another mechanism for 'deflecting' was expressed in descriptions of other things that could be worse or worse for others. Five participants in all focus groups reflected on the possibility that the breast cancer could have killed them, for example:

'… But like you say, when you re-evaluate your life afterwards and think on a scale of things, what's a scar? You know, we could have been dead...' (F1:P4:L460)

There was a recognition that not everyone survives this disease and that they were taking part in the group because they were fine, which produced a 'making the most of it' frame of mind. Although, some participants also described other things in their lives they were more concerned about, and that the 'odd scar' should not be worried about.

Six participants also reflected on how it could be worse for other people who may be seen in other Trusts or those who had never seen their consultant, while two described if they were in their countries of origin, that these treatments and this operation would not be available to them, or not without a

large invoice at completion (F3:P13:L716; F3:P14:L712). Two participants discussed how they thought it would be worse for younger women going through this (F2:P7:L556: F2:P9:L600). Participant 6 referred to a friend who had undergone an implant reconstruction and radiotherapy:

'… And she thinks she's going to have to go back and have some more surgery and have it changed and it just made me think, "Thank God I didn't have that" …' (F1:P6:L516).

5.8.4 Sub-theme: self-management

Four of the participants across all of the focus groups talked about activities they undertook to manage their own recovery or symptoms. Most comments were associated with the arm and the exercises they do to ensure mobility and reduce chances of lymphoedema. Other comments described becoming more active and how this had dispelled some of the fatigue:

'… But now, this year I joined the gym, then I feel better …' (F1:P3:L20).

This encouraged a sense of doing '*it for myself*' (F1:P1:L420).

5.8.5 Sub-theme: support

'Support' referred to the way that the participants were supported, and this sub-theme was expressed by ten of the participants. Some participants described being supported by friends and wider family, in order to protect those closer to them. Participant 1 received most support from her sister-in-law (who had been her best friend at school) due to her parents being too emotional to support, although she details how close-knit this experience has made them as a family and that she also receives '*fantastic*' support from those she works with (F1:P1:L299;L306). Participant 4 also described how her friends and work friends were more supportive than her family, allowing them to go wig shopping and calling them when she was distressed (F1:P4:L317). Participants gave specific examples of support from friends and family, such as:

'… And I thought, you know, my mum, my mum, bless her, she was like the police! "You've got to stretch, you've got to do this," she wouldn't even let me hoover two years later …' (F2:P7:L367).

'… when I was having radiotherapy my sisters were all scattered all over the world, so they came to take turns to come with me to hospital just to give me that support …' (F2:P10:L621).

Partners were also singled out as specific sources of support, for example:

'… he was just really supportive of it, yes. That helped me overcome the whole thing...' (F3:P11:L821).

There were also descriptions of being supported by other patients and that this had been very much a positive experience, preparing them for the next stage of the treatment and giving an insight into what was to come. Support groups were also discussed; one woman stated she did not *'… want to sit here talking about this …'* (F2:P7:L369), while others felt this support mechanism had helped. The participants also described supporting others through their treatment, and this extended to the supportive environment of the focus groups where the women exchanged tips for buying bras found to be more comfortable (padded ones with soft material).

5.8.6 Summary of theme: Coping strategies

Participants in this study described mechanisms they used to cope with the effects of having cancer and treatment. This included prevention of lymphoedema with arm exercises and not carrying heavy bags, dealing with fatigue and pain, and buying different clothes suited to the new anatomy. Participants also described the benefits of having a positive attitude and finding the positive in the situation they found themselves. A process of deflecting away from the experience by blaming other things such as age or ethnicity for effects such as poor wound healing, fatigue or reaction to radiotherapy, was also expressed as a way of coping; justifying side effects.

'Justifying' was commented on by some participants, and a number of issues were explained and defended through the use of these meanings. Each treatment and its completion was thought to be a milestone, and issues regarding self-management all related to exercise each women undertook, either in general, or in regard to the arm, and some found humour useful when discussing their post-reconstruction breast issues. Support was sourced from friends, family, work colleagues and women who had undergone this experience. Support was deemed helpful and all detailed good circumstances; nobody commented on a lack of support or not receiving enough. Support was sourced by the participants and they used different people for different reasons; some seemingly protected their family by disclosing more to friends and work colleagues, while others felt much closer to their family as a result of the treatment. Worse things were discussed within this theme and the women realised that they could have died from their cancer, that other issues were more dominant in their lives and how it could be worse for others.

5.9 Theme: Information

There were 80 statements relating to the theme *Information* (Figure 5.7). This included examples of when the participants felt well-informed and prepared, and also examples of a lack of information when participants were not adequately prepared, when they actively sought information, were concerned by unfamiliar language or information, or given too much information instead of being guided through the treatment by the professionals. They spoke about the timeliness of information, being unable to take information in a certain points.

Figure 5.7 Theme of Information with associated sub-themes

5.9.1 Sub-theme: good information

Four participants commented on 'good information', essentially that they were informed about what would happen to them at different stages of their treatment. These comments appeared within all three of the focus groups, although one participant contributed three of the six comments. 'Good information' that the participants felt had informed them came from different sources. One of the women even watched her procedure on DVD:

'… So I watched the DVD of the whole operation the night before I came in. So I knew exactly what I was letting myself in for. That was fine. And I'm really glad I did that, because I wasn't scared …' (F2:P7:L538).

It was not always clear where the information came from. This may have been information imparted by the medical team or from outside sources, for example:

'… *And the doctor said it will be pain …'* (F1:P2:L99)

'… *and, you know, I knew I'd lose my hair …'* (F2:P7:L1035).

Although slightly ambiguous, it is thought a healthcare professional was responsible for delivering the information regarding Participant 12's comment, as detail to this level is unlikely to be delivered through another

route. The comment relates to the worry attached to the breast being lumpy and not knowing what is going on inside it, but the reassurance of the information given and access to the medical team appear to dispel concern:

'… Well because I've heard that that might happen, and at the moment, because I'm still in regular check-up mode, any issues I can bring up there anyway …' (F3:P12:L774).

5.9.2 Sub-theme: poor information

'Poor information' was described in 58 statements and was concerned with not being able to take in the information, being concerned by the medical advice, not informed of lymphoedema, the need for more information, not expected, seeking information, too much information or unfamiliar.

Participants spoke about not being able to take in information. This included information that healthcare professionals had given to them that they had not been able to digest due to the enormity of the words, their associated meanings and the timing for processing the information:

'… they say, 'You have cancer,' I don't know if everybody else afterwards they took you out to a room and you're crying, my husband and everything else. And they're trying to explain to you what stage you have and everything. Don't bother. Who listened? Did anyone listen at that point? ...' (F1:P4:L495).

'… But you don't always take it in …' (F1:P5:L512)

'… I just heard chemo ... I think, for me, yes I probably didn't hear much. But then I think I would have, I had to hear it a few times for it to actually make sense. So I might have gotten a few words from the first one, a few more from the second one and then …' (F1:P2:L435) *'… And the oncologist said, "I did actually tell you this before." …'* (F1:P2:L310).

'… No you don't … It takes a few months of those visits before the penny drops and you actually register all that's going to happen to you. Those first few months you do sort of rabbit in headlights …' (F1:P4:L496).

There were also comments that related to 'poor information' and being more concerned at the medical advice. One statement related to information that had been given about lymphoedema, the medical advice was not attributed to any group (e.g. healthcare professionals or support group), but the information clearly had an impact on the experience:

'… just because they kind of filled me with horror at the idea of my arm all swelling up if I banged it really badly or bruised it or carried something too heavy or, you know, shocked it in some way...' (F2:P7:L140).

Other comments related to lymphoedema and not being given information about this condition. Interestingly, two out of the three statements were from Participant seven. She illustrated above that she received information regarding this possible condition, and yet states within this category that she had not received any information about lymphoedema:

'… I don't think anyone had talked about lymphoedema at all. Now I might be (doing) someone a disservice. Maybe I was just kind of choc-a-bloc full of info...' (F2:P7:L134)

Five participants across all three focus groups specifically discussed needing more information, or someone to talk to, for example:

'… But you do have these doubts and fears and that's normal. So it would be nice to be able to talk freely to somebody about it …' (F1:P5:L507)

'… I think I should have made more of the support on offer, looking back on it. I think I might have found it easier...' (F2:P7:L644)

There were a few comments related to not having the information after surgery; one participant felt all the information was delivered in the pre-operative phase, another felt she was not prepared physically and third said she was not sure why she was being asked to undertake post-operative exercises:

'… I think it's a bit like when you're having a baby, everybody focuses on your pregnancy and the labour. And you've got loads of information. There's nothing you don't know. But no one tells you what it's like afterwards. And it's a little bit like that …' (F2:P7:L537)

'… I didn't feel that I was given enough information in terms of how I would feel, not mentally, but physically after the surgery...' (F2:P9:L577)

Within the remainder of the comments there was a theme of a lack of information that translated to feeling less prepared:

'… But I think it is just that. If you had a full, a fuller picture of – none of these things are showstoppers, but don't worry when it happens to you, that would be really nice. And it might not happen to you. All women have different experiences …' (F2:P7:L559)

'… I do still wish that I had a bit more information beforehand...' (F2:P9:L594)

'… So it's, it would help to, you know, for people to know that, what might happen...' (F2:P10:L618)

Six participants over all three groups described not being prepared, or that some experiences were not as expected. Most comments referred to experiences post-operatively and physical effects on the body, for example:

'… when I had my breast reconstruction, they said, you know, there will be some numbness. But I didn't realise there would be like numbness as

in I would not feel...' (F2:P9:L169) and *'… You didn't tell me that I would be numb, numb...'* (F2:P9:L175)

'… They're not major, they really, really aren't. But you're not prepared for that. So it does come as a bit of a, "Ooh, I didn't realise that having your lymph nodes removed would mean that I have very little sensitivity here."...' (F2:P7:L541).

In addition there were comments about the abdominal donor site, relating to the size of the scar, how it feels and about the new umbilicus that is surgically constructed, for example:

'… My only thing was that I had – I wish I had been prepared for how I was, how it was going to feel because I was just, you know, simple little tummy tuck and a little thing. That's the kind of way they sold it to me, for want of a better word. And I was just thinking, "Oh yes great, I'm going to come out looking fab." And so, yes, okay, I came out looking fab, but how I actually felt was just, I just wish someone had told me how it was going to feel, because I kept thinking something is wrong, is it all stuck in there or something...' (F2:P9:L596).

There were a number of comments relating to the bandages used post-operatively and these were not expected by some of the participants, nor was the intense post-operative care delivered, or the convalescence period, for example:

'… I wasn't expecting to be so, I was expecting to be packed, like bandaged up and I wasn't expecting everything's out and just you can see the stitching and everything...' (F1:P2:L6)

'… so I appreciate that has to happen obviously, but I hadn't really, I wasn't really prepared for it. I hadn't realised it was going to be quite like that...' (F3:P12:L653)

'… I think from my point of view, I think I would have liked to have known a little bit more about the—immediately after the operation, because I didn't really know what to expect. ... But if—think perhaps if I'd known ahead, it might have helped …' (F3:P12:L763)

'… not knowing that after the operation I'll have to learn to walk again. That was something I wasn't prepared for at all ... You know, that was quite shocking actually, not knowing that after the operation...' (F2:P10:L211)

'… they said I would get back to work in a month, but it took longer than that...' (F2:P7:L372)

Within this meaning there appears to be dissatisfaction with the cosmetic result of the breast reconstruction, for example:

'… But I just still feel like this is not how I believed I was going to look …' (F2:P9: 587) and *'… But it's just like I was led to believe that I was going to look a certain way, but I don't …*' (F2:P9:L581)

'… I kept thinking, "I wish someone had really informed me beforehand"...' (F2:P9:L578)

'… just feel it's awful really what I'm going to say, but I feel sometimes it's like you sold me something but I didn't get what you sold me. Does that make sense? ...' (F2:P9:L579)

Three participants in two focus groups commented that they actively sought information from the Internet, friends and healthcare professionals, for example

'… I just went on the NHS website and just, and I looked at the Macmillan website to have a look at what other people were saying and what I might experience...' (F2:P10:L619)

'… I said to my consultant. I said, "Why does my stomach still feel weird? ... Am I supposed to feel like that?"...' (F2:P9:L173)

'… because I have spoken to people who are waking up and are very hot every hour...' (F3:P12:L659).

Participant 5 was the only one to comment on having too much information and in the wrong format. The nurse specialist gives the patient on diagnosis a raft of information within charity booklets and, until this comment, there was no reference to the amount of information or if it was in a user-friendly format, except for reference to the DVD being useful (section 5.9.1):

'… they gave me a big pack of all the booklets and I had all the information I could possibly need. ... "Any questions, come back, just ring up and say, you know, you can come to the outpatients' clinic, I can fit you in."" So I just I was given all the information I could cope with, perhaps more than I could cope with at the time! ...' (F1:P5:L511).

There were two comments about the experience being 'unfamiliar' and not understanding the information; both were within the same focus group:

'… Which is the DIEP flap? I'm getting a bit confused again. …' (F2:P9:L604)

'… I was told I might have radiotherapy. And that was something that I'd never known anyone to have. So it was something that I had not explored. And, to me, it was better than chemotherapy. Because chemotherapy, you hear a lot, you know, hair falling out. So I thought radiotherapy can't be any worse...' (F2:P10:L1001)

5.9.3 Sub-theme: would recommend

Most of the participants 'would recommend' aspects of this treatment to other women, especially the immediate reconstruction, for example:

'… Yes, I had a crap time, but I would still recommend it. It is an extraordinary thing...' (F1:P2:L432)

'… Well I would say, "go ahead"...' (F1:P5:L509) and *'… Yes I would advise it. If I had to advise somebody, I would say, "Yes just go for it." …'* (F3:P11:L717)

'… and I also would go with this choice, yes to have it done, two in one, everything like three in one, two in one is good...' (F3:P14:L718)

'… Considering how severe the surgery is, you know, it's major surgery, etc., it's not that bad really, you know... I'd have it done again …' (F1:P4:L482).

A couple of other comments regarded showing those who were to have this operation that there was nothing to be frightened of, for example:

'… And I'd show it to anyone who was thinking of having, who felt, you know, was wondering about having it, just to show them that it's nothing to be frightened of...' (F1:P5:L857).

5.9.4 Summary of theme: Information

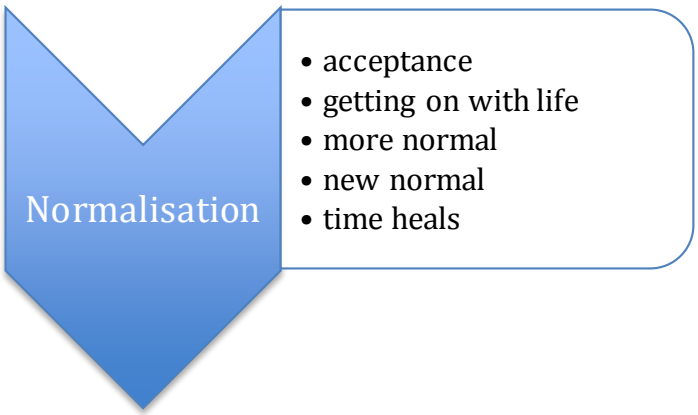
Information refers to the amount and the detail of the information the participants were given about their treatment, and the information the participants would pass on to other women. Good information came from outside sources, such as a DVD and a website, in addition to information that had been delivered by healthcare professionals. Poor information was a larger category, which included too much information at the beginning of their diagnosis or treatment when they could only concentrate on the word 'cancer'. Not enough information was given about the immediate post-operative period or the bandages that would be used. However, the majority of the participants who commented about this (eight of the nine) would

recommend this operation to others, were pleased they had undergone it and stated the immediate reconstruction option was the optimal option.

5.10 Theme: Normalisation

Normalisation was expressed in 125 statements, and expressed in some way by all of the participants. Normalisation was made up of five sub-themes: 'acceptance', 'getting on with life', 'more normal', 'new normal' and 'time heals' (Figure 5.8). Normalisation is the act or process of normalising or bringing back to a normal state (Collins 2014). Normalisation was identified as a theme linked to the other themes in a complex web of interaction. Maintaining control over the way we look to others, over whom we share our 'abnormality' with, looking different, feeling different, entering the healthcare system and relying on healthcare professionals, etc., may all affect our departure from, and maintenance of, our normal state, but Normalisation stood out as a distinct theme. Normalisation in this study encompassed acceptance of the effects of treatments, and getting on with life and seeing cancer in the context of a life being lived. Participants spoke about feeling normal and getting back to normal, including how hard that can be. Things that reduce the disruption to normal life, such as having one operation or using one's own tissue, were also discussed, as was what represents a new normal and an acceptance of that process. Time was also spoken about in relation to the physical and psychological healing effect of time.

Figure 5.8 Theme of Normalisation with associated sub-themes



5.10.1 Sub-theme: acceptance

Almost all of the participants (11 of 14) made reference to accepting the effects of the treatment. This was not simply referring to how the participants may have been changed as a result of having cancer, or cancer treatment, (see *Being changed*) but about how this change was accepted as part of the process of *Normalisation*. Participant 7 talked about how the scarring from the surgery could be seen at times, but she made it clear that she had accepted this; it has not changed her behaviour and she was not particularly 'bothered':

'… I'm just conscious of ... if you're in a dress for the evening or something like that – it wouldn't stop me wearing it ... if anyone asks I'll just tell them, so, you know, I'm not that bothered …' (F2:P7:L43)

Participant 11 also talked about the effect on her clothes; not feeling 'right' in tight t-shirts anymore, but she also added, *'… it doesn't bother me that much …' (F3:P11:L52).*

It is important to note that both these women expressed some hesitance or ambiguity by adding *that* as an adverb, saying 'not that bothered' and 'that much'. This ambiguity may have something to do with the fact that these women are not too far away from treatment and possibly still in the process of adjusting to life beyond a cancer diagnosis; the process of normalisation. Participant 4 made this process of acceptance clear when she said:

'… At the beginning ... you could feel it and you'd stop more often, whereas now you just get used to it...' (F1:P4:L82).

However, there could also be an element of acceptance in context; the caveat that things are good considering: considering having cancer, major surgery, chemotherapy and radiotherapy, for example:

'… You know, I think it's just a by-product of having that done. And if that's all I've got to live with, okay, fine, that's not bad …' (F1:P4:L493)

'… You know, it's part and parcel, you know …' (F2:P9:L603)

'… on the whole, I'm alright …' (F1:P5:L120).

Ultimately, when considered in context, the treatment was seen as having *'… more advantages than disadvantages...'* (F3:P11:L778) and an acceptance of being good enough, *'… Well I don't mind, it's better than nothing actually …'* (F3:P14:L728), *'… I can't be like greedy …'* (F3:P14:L657) and in relation to the skin feeling different on the donor site *'… But I don't care …'* (F1:P2:L438).

But, as seen in *Being changed*, we share our lives with those around us and the participants also spoke about the normalisation process experienced by others, the acceptance of others and the corresponding effect upon themselves, for example:

'… I mean my kids have seen me, you know, if we're wandering around or on holiday, and they don't bat an eyelid. And so I kind of think well why should I? ...' (F1:P6:L345)

'…My husband, bless him, fine … So intimacy is not a problem, which is strange because I really thought it was going to be a problem...' (F2:P9:L797).

5.10.2 Sub-theme: getting on with life

Eleven of the fourteen participants referred to getting on with life in 43 of the statements. 'Getting on with life' included the way the participants described how they continued to live a normal life, putting the cancer and treatment behind them, for example:

'… Right now, I'm fine, you know, get on with it …' (F1:P4:L893)

'… But I must admit I tend to still do things ... My mum keeps telling me, "You're not like before." But I still try to carry on...' (F2:P9:L183)

'... I know I shouldn't carry too much, but you forget, you know, and you do …' (F1:P5:L32)

Participant 7 spoke about not wanting to go to a support group where she would continue to talk about the cancer instead of getting on with life:

'… I know there are lots of support groups out there. And I went to xx a couple of times. And I hated it. I just hated it. I was just like, "I want to get out of here." I do not want … I don't really want to spend a few hours of my life talking about it...' (F2:P7:L566).

Participant 4 expressed this as making the most of life, *'… get on with it, life's great, so enjoy, make the most of what I've got …'* (F1:P4:L895).

'Getting on with life' was also directly expressed as getting back to normal, *'… But yes you do kind of get back to normal...'* (F3:P11:L705).This was often specifically associated with getting back to normal after the operation:

'… actually once you are up out of that bed and you've taken a few steps, even though it's shuffling, it's never as bad again...' (F2:P7:L162)

'… I sent a picture home to my family. And they were like, "Oh my God, already sitting up"...' (F1:P2:L410)

However, it was acknowledged that this was not necessarily an easy process:

'… that's something I'm looking forward to, like another year and hopefully I will slowly get back to how I was...' (F3:P14:L820)

'… It's really emotional because you feel like it's stopping you from living your life...' (F1:P2:L414)

'… But like you sort of said, the black moments …' (F1:P4:L472).

Participant 7 had to take a significant amount of time off work before she felt ready to get on with life:

'… I knew I couldn't handle the pressure of work or the travelling – so I'm kind of in the process of looking for a local job now. I feel, I've been home for a year now, so I kind of feel that I feel back to normal, a lot more back to normal, that I can actually go back to the working world again …' (F2:P7:L387).

While Participant 9 found returning to her studies quite difficult:

'… So I was in the middle of my second year. And going back to studying was difficult for me …' (F2:P9:L196).

However, this could also be seen as a deliberate retreat from life to concentrate on the treatment, or at least finish being in the sick role before getting back to normal:

'… I mean I was, I was off work for a while, for about nine months after everything… I just wanted to finish everything and then go back...' (F3:P12:L396).

'Getting on with life' was also relevant for others, where friends and family were also moving away from the cancer experience:

'… "Yes, you had it, you're fine now." That's how she sees it, she sees it. "You're fine now." If I say I've got a twinge, she's, "There's nothing wrong with you." But that's how she sees it now, mum is mum again and that's it. …' (F2:P9:L955)

'… Although they don't care, they think I'm well enough to do everything again – so I'm back to square one...' (F2:P10:L959).

However, some aspects of life for others had to continue regardless of what was happening to change the life of the participant:

'… Yes because I got called for surgery the day I was meant to take my holiday. So their dad had to take them instead. That was a bummer! ...' (F1:P6:L365)

Feeling normal supported the process of getting on with life. This included having the reconstruction done at the same time, meaning that there was no time that the woman would be without a breast:

'… my little boy, who was only eleven, because every night before he went to bed, I used to lay on the bed and read with him, and he always cuddled up to this side. And this is the side, and I thought, if I don't have anything there, since he'd been a tiny baby he'd always cuddled up to me there and it's for his benefit as well as mine, because we were going through a lot and he still needed that security that I'm mum and I'm not going anywhere …' (F1:P6:L521)

'… Yes, of course is, you know, this is for a woman, very important… It gives you a lot of confidence...' (F3:P13:L646&648) and *'… it helps, you know, because this is part of your feminine and when you feel like this, there's something missing, you're not like other women …'* (F3:P14:L657)

Having the surgery as one procedure was also seen to enable the participants to get on with life by causing less disruption, for example:

'… And it was like it was good like to have all in one instead of coming again and the anaesthetic, you know, and leaving your home...' (F3:P14:L700)

'… Get it over and done with in one fell swoop … You don't have to go back again. ...' (F1:P4:L463).

5.10.3 Sub-theme: more normal

As part of the specific discussion about elements of the procedure, several of the women referred to the use of their own tissue in the reconstruction as an important way of normalising the process, for example:

'… Okay it's my own tissue, everything is going to be mine. That's what I was worried about having something alien in my body...' (F1:P2:L405)

'… Because your own body's not going to reject your own body...' (F1:P6:L499)

'... And safer. I think it's safer if you've got tissue...' (F1:P2:L515).

5.10.4 Sub-theme: new normal

As part of this normalisation process, 11 of the participants referred to what can be described as their 'new normal'. Although this could be linked to *Being changed*, in this context, the women refer to their acceptance of the new normal and how this became who they now are. Sometimes, this was expressed in defiance of the physical changes, for example:

'… I just look at it now as this is who I am now. I don't look at it – I don't try and think, "Ohhh." This is just who I am...' (F2:P9:L595)

'… Compared to before, when there was nothing wrong with my body at all, now I just, I love it with the scars and everything.... I like my scars. Shows I've lived...' (F1:P3:L449).

At other times, the 'new normal' was expressed as normal but with the caveat that it is not actually like before:

'… I'm just back to normal. I'm doing exercise, working, but only like shopping I can't carry heavy things in my left hand...' (F3:P14:L224)

'… I look at mine, and it looks just like a new belly button ... It looks more of a hole than I had before … But now I don't really notice it. But it just, now it's just there...' (F2:P9:L874).

However, the experience of having cancer is never far from the 'new normal':

'… some days when you stop and think or when you hear about somebody else has breast cancer, you kind of feel for them, because you know what you've gone through …' (F3:P11:L704).

And the new definition of normal may not be the accepted norm:

'… My little boy was quite funny because when we was explaining to him what's going to happen … he went, "So if your tummy is going to be up here," I said, "Yes," he said, "If you're hungry, do you go 'Ooh?' Like when you rub your tummy and you're going, 'Oh I'm a little bit hungry.'" ... If I sit and (rub my reconstruction) … And he says, '"Mum are you hungry? Shall I go and get you something to eat?"...' (F1:P6:L343)

5.10.5 Sub-theme: time heals

Time in this context was referred to by 12 of the participants, primarily in two ways; the length of time that the healing process took and the fact that time does make a difference. The time taken for things to heal was commonly referred to in terms of years:

'… I've got a very long time to recover. I got the operation in 2008. Now it's '13. …' (F1:P3:L19)

'… And I haven't felt really like I've been getting back to the old X until this year. …' (F2:P7:L949)

'… And I have to say I'm feeling a lot better now. … Five years ago in December. ...' (F3:P11:L960)

Even the post-operative effects took a long time to wear off, or the time it took for the soreness associated with radiotherapy to settle, for example:

'… It took me about three or four months to get back, couldn't sleep at night …' (F2:P10:L958)

'… In fact, not being able to sleep on my right side went on for ages … really ages...' (F2:P7:L947).

Running through the comments about how long healing takes, is the impression that it took much longer than expected. Participant 9 openly expressed this:

'… It takes a while, yes. And I think you kind of almost believe the hype, because you expect to be okay, "I'm going to be ready once this all calms down," but you're not...' (F2:P9:L954).

But time is referred to as the great healer, it was possible for the participants to *'… over time, look back and laugh about it …'* (F1:P4:L475), for example:

'… each day you felt better, you know, you felt much better the next day and the next day and the next day...' (F3:P12:L765).

However, the participants also acknowledged how difficult it was at the time:

'… And if you'd asked me that question shortly after I'd finished radiotherapy, I would have had a different answer. I think it's just been so long now that I've forgotten how traumatic it was for me...' (F1:P4:L944)

'… But at the time ... it's not quite so funny, you know …' (F1:P4:L476).

And within the focus groups the participants were keen to reassure each other that, given time, most things improved:

'… But you're a year behind me and mine have totally gone now...Yes totally, totally gone...' (F2:P7:L950).

5.10.6 Summary of theme: Normalisation

Normalisation refers to the way the participants described aspects of the experience associated with returning back to a normal state. Normalisation can be seen as a process, incrementally moving away from the experience towards the normal state, even if that normal state will never quite be like before. Less initial disruption helped the process of normalisation, such as having one operation and using one's own tissue. Normalisation also occurred for those around the participants, situating the process in the context of their lives and even shaping a newer stronger identity. There was general acknowledgement that this was not an easy process and often took years, but that time does heal and a new normal state ensues because ultimately *'you do kind of get back to normal.'* (F3:P11:L705).

5.11 Theme: Trust/faith in healthcare professionals

There were 81 statements relating to healthcare and the relationship with doctors and nurses (Figure 5.9). 'Being done to' and 'being told' were both aspects of healthcare that took away control, but which could also be seen as positive aspects of care. Trust/faith in healthcare professionals is concerned with good or poor aspects of care and the trust placed in healthcare professions.

Figure 5.9 Theme of Trust/ faith in healthcare professionals with associated sub-themes

Aspects of 'good care' included being given choice, time to make decisions, apologising when things go wrong. Poor care included painful follow-up tests, poor advice and a mention of being dehumanised during treatment. Having faith in the healthcare professionals was mentioned by the participants and the effect that feeling safe during treatment and care had after follow-up or treatment stopped.

5.11.1 Sub-theme: good care

'Good care' was primarily associated with healthcare staff and commented on by 12 of the participants. Participants described being given a choice, enough time to make decisions, and there were two comments within the same focus group regarding the general practitioner apologising for their part in delaying the diagnosis pathway. However, one participant stated the apology was enough or somehow made up for the error, whereas the other participant felt this was not enough:

> *'… She said sorry. Sorry doesn't mean anything …'* (F1:P2:L448)

> *'… No. But at least she did. She did …'* (F1:P4:L498).

Choice in breast size was discussed positively and one comment related to having the support of the surgeon if the participant decided to alter her type to reconstruction to implant only:

'… I think if I'd said I really wanted to have implants, they probably would have said, "That's your decision." …' (F1:P2:L404).

Good care included having enough time to make decisions, not feeling rushed into making the decision as to whether they had this type of reconstruction, or nipple reconstruction:

'… I think that is one thing that is quite nice, that they, there isn't a date for you to make your mind up… And quite honestly, like everybody here, you have enough that you're dealing with in the first place … So, and I think that's quite a nice option to know that it's there ... It's left for you to sort of think about it and come back...' (F1:P4:L470)

'… I felt that I had the time, I was given the time to make an informed decision …' (F2:P9:L956)

'… Then I had a chance then at the end of that to say did I still want it...' (F1:P4:L466).

There were a number of general statements concerning care and some that could be associated to good care delivered by the ward nurses within the post-operative environment, for example:

'… And they were so good at knowing what you had to do and when you had to do it ... and they know exactly what they're doing …' (F2:P7:L161)

'… The nurses were very kind and I want to appreciate them, yes. They understand us...' (F2:P8:L569)

'… they were great, fine, really helpful, very concerned that you're okay and, you know, you can get comfortable for sleeping...' (F1:P5:L503)

Other good care was associated with the team and Trust as a whole:

'… I thoroughly enjoy coming here, if that's a word you'd want to use, but at least if you're going to go somewhere, it's nice to go somewhere that is, that you feel people care, that genuinely care. You know, not like you're just a number or a ticket or anything else …' (F1:P4:L485)

'… But no, they were all very good. I felt my recovery was really due to the excellent service I got. And the GP, from xx, from here, and the three— the two surgeons and the doctor who looked after me. And the oncologist and all the nurses...' (F1:P5:L513)

'… I think the whole team from beginning to end are really, really supportive...' (F3:P11:L715)

'… What I was so confident and positive with all the care of the nurses and the lady who saw me and like between me and the doctor it was always, it was perfect …' (F3:P14:L755)

Three participants discussed the National Health Service being a benefit and the positive process they had experienced of being referred from another Trust to the one where they had their operation:

'… But generally I think we should be grateful for everything, for all the support, definitely, I would really give it to the NHS. I know someone who had cancer and she did everything privately, and if we compare everything, I still feel I'm getting more support through NHS …' (F3:P11:L752)

'… And I think the support of the National Health was fantastic. You know, the doctor and the liaison between xxx and xxx, it was great. There were no hiccups or problems or anything. So it was very good …' (F3:P12:L749)

'… But everything was really joined up well. There was no, you know, everything followed on quite neatly. I had the, you know, the appointments

with the plastic surgeon in plenty of time to really discuss everything. And then think about it and then come back and talk more …' (F3:P12:L661)

Some participants mentioned the surgeons by name and had praise for them individually, for example:

'… they were very, very, especially Dr xxx. … And they were very, very good ...You feel they are caring about you...' (F1:P2:L444) and *'… Yes, that's mine as well, he's a very good doctor …'* (F1:P3:L457) and *'… Dr xxx is wonderful …'* (F1:P5:L510)

5.11.2 Sub-theme: poor care

'Poor care' was commented on in relation to procedures such as mammography and radiotherapy. Two stated that follow-up mammograms were painful (P12, P14); others spoke of how treatment was impersonal, for example:

'… I found surprising and slightly demoralising, was the radiotherapy just because of the mechanics of the treatment and that it is every day. And you are in and out. And it is a bit impersonal …' (F2:P7:L994)

There were two comments from Participant 12 about 'poor care' she had experienced on the ward in the post-operative setting:

'… But I couldn't really get it, I couldn't really reach it. ... Or a way of getting water that you could have from a bottle …' (F3:P12:L273)

'… I just felt hot and uncomfortable and like I, you know, but I guess it is a necessary process. But anything to make you feel a bit more comfortable would be good …' (F3:P12:L274)

There were six comments from four participants regarding poor advice given by the medical team. These ranged from advice from the general practitioner,

to an outpatient conversation with the surgeon, to being discharged with their drains post-operatively. There does not seem to be any consensus or agreement that there is one particular source of poor advice:

'… I wish I'd have stayed in with the drain ... but I think that they should have actually said to me, '"No." They knew that there was a problem...' (F1:P6:L128)

'… particularly you don't want a medical person feeling sorry for you, because you want them to be positive, because that's how you feel...' (F3:P12:L721).

5.11.3 Sub-theme: trust professionals

Nineteen comments were within this sub-theme. The meanings of these statements were associated with faith in the professionals, feeling safe and difficulties at the end of treatment when care ends, for example:

'… So I think that would be helpful to know as well. But it's not, "Hey wow, you've had your surgery, you've finished radio," and I really do think that people just think, "Oh she will be back to normal." And there is a massive expectation on you because people have made an effort to help you and support you. And it's like, "Right well we're off now. Off you go." …' (F1:P6:L351)

'…I felt cut off when the doctor said, "You don't have to come back for a year," after having that support and chemotherapy and the operation and the radiotherapy, you just suddenly feel you've been launched on the ocean by yourself and lose everybody. ... I had more trouble emotionally afterwards when I felt I was on my own …' (F1:P5:L505)

'*… And when we finished, I feel lonely, you know! Believe me, yes, because I was surrounded with, you know, all the doctors and they're taking care of you …'* (F3:P14:L758)

'… I think it's scary as well when you finish everything and then you're only seeing the doctor once a year … because you kind of feel that you were looked after and now you're on your own...' (F3:P11:L760)

However, Participant 12 thought that there was opportunity to bring issues up at outpatient appointments:

'… because I'm still in regular check-up mode, any issues I can bring up there anyway …' (F3:P12:L1055).

There seemed to be faith stored in the professional and a number of comments encapsulate this, for example:

'… I felt very well guided and I had absolute trust in my consultant...So when it came to surgery, I was definitely guided by him...' (F2:P7:L625)

'… I saw the doctor, he was so confident and, you know, I trusted him a lot, yes. And I said, "Let's go for it."...' (F3:P14:L701)

'… gradually came to the idea that this is probably the best solution. And I just had all my faith in my consultant who was very good all the way …' (F2:P10:L1054)

'… So he gave me the security and confidence that, okay, he's a specialist and he knows what he's talking about. …' (F1:P2:L341)

'… So as soon as somebody in authority said to me, you know, "You should actually be moving as much as possible," I was like, "Okay then, great."...' (F1:P2:L411).

There were also three comments about decisions and choice, including one comment relating specifically to the fact the participant was going to have radiotherapy post-operatively:

'… I wasn't sure whether I should have the operation, sorry, the reconstruction after, because potentially there was, potentially some damage to the tissue by having the radiotherapy. But then after more discussion and talking to my consultant, you know, they strongly recommended doing it together. …' (F3:P12:L662)

'… we didn't have decisions to make. It was pretty much, "This is what's going to happen." I think it would be harder if you did have those decisions to make …' (F2:P7:L639)

'… So it was quite nice not to have to ... They said implants are not to be used ... So it's your decision is made for you …' (F1:P3:L452).

5.11.4 Summary of theme: Trust/faith in healthcare professionals

Trust and faith in the process of healthcare was attributed to individual doctors, nurses, communication between departments and externally to other referring Trusts. A small number of participants celebrated the National Health Service and also commented on faith in the professionals who cared for them, including being grateful. There were a few statements associated with the end of treatment, and feeling alone and abandoned, which seems likely after one has trusted and felt supported by the team and hospital care. The few comments on poor care are a small mixture relating to a variety of situations, including the general practitioner.

5.12 Overall satisfaction of reconstruction

At the end of the focus groups participants were given a Likert scale in order to rate the overall satisfaction with their reconstruction. While it is appreciated that this Likert scale is a broad and simplistic tool, it was included in order to characterise the participants. As the results below illustrate (Figure 5.10), seven of the participants (50%), (and all the members of focus group one) ranked satisfaction 10 out of 10. The mean for these scores was 8.8, with the mean for focus group one being 10, focus group two being 6.8 and focus group three was 9. Participant 10 ranked satisfaction at four, and her score appears quite different from the others, although focus group two appear

overall to be less pleased with their reconstruction. These scores are presented to give an overview of participant satisfaction in relation to their breast reconstructions at this time point.

Figure 5.10 Reconstruction satisfaction rating

5.13 Follow-up telephone call

Three participants were telephoned one week after the focus groups as arranged, but no additional comments were elicited.

5.14 Case note review

At the end of the study a case note review was carried out in order to identify documented evidence of complications and side effects associated with this combination of treatment. All the case notes of the 14 participants were requested from the medical records department of the Trust that they were operated at; however nine of the 14 medical notes were available for review. It was not felt that the resources involved in escalating and sourcing misfiled notes could be justified for this doctorate study, although this was escalated to the medical records manager of the hospital. The case note review was to

consist of identification of date of primary surgery and follow details of correspondence, hospital contacts, investigations and medications from a secondary care perspective.

On review of the nine notes one of the participants required surgical intervention for wound dehiscence pre radiotherapy. There was no other documented evidence of major complications of such as severe fibrosis or flap necrosis. Revision surgery was commented on for symmetrisation in four sets of notes. The case note review was consistent with the discussions the women had in the focus groups.

It is possible that women who suffered severe complications were less inclined to participate in this study and this influenced the positive findings, however response rates were high and the opinions expressed were from the majority of women that had this treatment at this Trust. This qualitative study is not generalisable but explores the experience of the women who participated.

5.15 Summary of chapter

This chapter detailed description of the participants along with analysis of data collected during the focus groups. As the participants had relatively little to say about their combination of treatment, but had important experiences related to their breast cancer experiences more generally, this additional data was analysed within the six themes of *Being changed, Control, Coping strategies, Information, Normalisation,* and *Trust and faith in healthcare professionals*. It reveals the physical, psychological, social and behavioural effects of the breast treatment. Shock on diagnosis of breast cancer was examined along with how the participants took charge of the situation through being positive, choosing who to tell of their disease, in addition to self-management strategies they adopted. They acknowledged they could have died from this disease, but also illustrated their situations could have been worse as they perceived it had been for others. The information delivered to these participants appeared well-suited to their needs, although they did

mention not being able to take on all the information given to them at diagnosis, that there was a lack of information that related to the immediate post-operative setting and possibly confusion regarding information about lymphoedema prevention. It was noted that, while all had accepted their new normal and many felt they had a stronger identity, this took years, but having had an immediate reconstruction and one that used their own tissue assisted with this phase of adaptation. In addition to stating they would recommend this treatment to others; they also mentioned an overwhelming trust in the healthcare professionals and system, along with feelings of relief that this operation and treatment was an option for them.

The crux of this research was to gain the patients' perspective of radiotherapy when given as an adjunct post TRAM and DIEP flap immediate breast reconstruction. The participants did not appear to be worried about this combination of treatment or any effects the radiotherapy had on their immediate autologous breast reconstructions.

Chapter 6: Discussion

6.1 Introduction

This chapter discusses the findings of the research in addition to comparing and contrasting themes identified within other related qualitative work. Additional information from this research builds on what is known about patients facing treatment for breast cancer and this will be discussed. The implications of the findings for clinical practice will be examined along with the strengths and limitations of the study, areas will be suggested for further research, and details on how the work will be disseminated will be provided.

6.2 Summary of study

The aim of this research was to investigate what women think and feel about the combination of adjuvant radiotherapy post TRAM or DIEP flap immediate breast reconstruction, and to highlight any possible consequences of this treatment. A review of the literature showed that possible ill-effects of this combination of treatment, such as fibrosis, occur from one year onwards post completion (Watterson *et al.* 1995), so it was decided to invite all women who had received their radiotherapy at a London cancer centre one to five years previously. The five-year cut-off point meant participants were able to recall their experiences in detail.

Three focus groups were held in a cancer support centre in London. The researcher was present at the groups, which were facilitated by a Professor of Nursing who is practiced in focus groups and also one of the research supervisors. Out of a potential sample of 30 women, 14 took part in these groups; six in group one, four in group two and four in group three. The tape-recorded focus groups lasted between 77 minutes and 99 minutes. The data were transcribed and analysed using Framework Method (Chapter 4).

Six themes were identified from the data: *Being changed, Control, Coping Strategies, Information, Normalisation* and *Trust/faith in healthcare*

professionals. These themes were present in all three groups. The findings showed that the participants had little to say around the combination of surgery and radiotherapy, but rather that they wanted to discuss the breast cancer experience in more general terms. The participants illustrated that, contrary to the literature, and in the context of the whole breast cancer experience, the magnitude of the TRAM/DIEP flap breast reconstruction was not such an enormity. The combination of treatments they underwent was relatively well tolerated. They appeared comfortable with the treatment received and would recommend it to women who found themselves in a similar clinical situation. Longer-term effects are unknown, as the data reflected experiences from years one to five post treatment.

6.3 What is already known on this topic?

Since this study was conducted, a systematic review of literature published between 2000 and 2012 regarding whether radiotherapy should be delivered in the pre- or post-operative setting, has been published. Berbers *et al.* (2014) discuss the implications of radiotherapy for those who have had implant reconstructions and those who have had autologous tissue breast reconstructions. After applying their selection criteria, their search yielded 28 studies. They stated their review encompassed all study designs with the exception of case studies, although there is no mention of qualitative data within this paper. The review primarily focuses on the effects post-operative radiotherapy had on implant reconstructions, although some consideration is given to the effects on autologous tissue reconstructions. In addition, they reviewed evidence associated with delivering radiotherapy before the reconstruction. These authors confirm the findings of the scoping review in this study; that there is a lack of randomised trials, sample size are small, and standardised outcome complication parameters are absent.

Berbers *et al.* (2014) conclude that, for autologous reconstructions, less fibrosis is identified if the radiotherapy is delivered prior to the reconstruction, but that the timing of radiotherapy had no significant impact on complication rates. They used quantitative data (weighted means and forest plots) and

concluded that there were no significant differences in complication rate, serious complications (which included flap failure), or worsening cosmetic outcome if radiotherapy was delivered pre- or post-reconstruction. However, on inspection of the detail, a caveat should be added as Berbers *et al.* (2014) (much like previous studies mentioned in Chapter 3) combined truly autologous tissue reconstructions (those that solely use tissue) with reconstructions that use both autologous tissue and a breast implant into their autologous tissue reconstruction category. Thus the clarity of reporting of this exact clinical indication is missing. Forest plots, which they included, summarised the studies, but did not detail the exact reconstructive technique or stay faithful to separating studies exclusively associated with the possible effects of radiotherapy delivered post-operatively to tissue-only breast reconstructions.

Within the paper cosmetic outcome from both patient and physicians perspective is mentioned, although the only additional information given was that no difference was observed between those who received radiotherapy before or after reconstructive surgery, and that there was no difference between implant-only or autologous tissue techniques. Berbers *et al.* (2014) did not include any qualitative data, preferring to categorise opinion as that deemed cosmetically acceptable or unacceptable. The Forest plot included, which refers specifically to patient satisfaction, contains a pooling of data from all four categories and it is impossible to decipher what patient satisfaction was when related to the delivery of radiotherapy on autologous tissue reconstructions.

Additionally Schaverien *et al.* (2013) published a systematic review of published literature that relates to outcomes of postoperative radiotherapy after immediate autologous breast reconstruction. This quantitative review also included literature regarding those post autologous reconstructions who did not have postoperative radiotherapy in addition to those who received radiotherapy pre autologous breast reconstruction. Moreover it reports on research associated with all autologous breast reconstructions, and includes studies of LD reconstructions as well as other tissue-only reconstructive

techniques; not purely on the outcomes for those post DIEP or TRAM breast reconstruction.

Schaverien *et al* (2013) analysed complications of fat necrosis, loss of volume, re-operation rates and cosmetic outcome. They did not appear to also inspect the themes I had included within my scoping review of acute side effects or co-variables. However as detailed within my scoping review, these authors also pick up on the diverse and non-comparable methods used to evaluate and report cosmetic outcome and suggest that Patient Reported Outcome Measures should be used in future studies. They state these measures were not taken in account within their review. They also concur that there is a dearth of good quality data within published literature, that much of what data is present is pooled and that there are no randomised controlled trials.

These authors discuss the literature and conclude that there are similar complication rates for patients who had immediate autologous reconstructions and post-operative radiotherapy when compared to those who did not receive radiotherapy, or to those who received their radiotherapy prior to having their breast reconstruction operation. They conclude that the majority of studies reported satisfactory outcomes for those who had radiotherapy after their autologous tissue reconstructions and therefore this combination of treatment should be considered by healthcare professionals.

Once more, there appears to be a deficit of information reflecting what this group of patients think and feel in relation to this combination of treatment. My findings provided rich data on a raft of issues experienced by these women contained within the themes: *Being changed, Control, Coping strategies, Information, Normalisation* and *Trust/faith in health care professionals*.

6.4 Original contribution to knowledge

Radiotherapy can be recommended and delivered as an adjunct to treating breast cancer for women who have undergone immediate TRAM/DIEP flap

immediate breast reconstructions. The literature is mixed and contradictory in places as to whether this combination of treatment has any effects on these autologous breast reconstructions. Also, different types of reconstructions are grouped together, and it is impossible to decipher the data for the individual techniques and clinical setting. Despite some studies highlighting the patient's point of view, most concentrate on the healthcare professional. None of these studies are qualitative in nature and none concentrate solely on the effects of these treatments from the patient's perspective. This appears to be the first study to do this and identified that women who had undergone this combination of treatments did not have major concerns that specifically related to this. None reported any lasting detrimental effect on the reconstruction from radiotherapy, despite direct questioning on several occasions during the focus group. They were prepared to be critical of other aspects of care and were not reticent during these open conversations. These women did discuss issues regarding their breast cancer experience as a whole: these will be discussed in detail below.

6.5 Women's experience of the effects of radiotherapy on breast reconstruction – the research question

Comments from the participants that related specifically to the effects of radiotherapy on their breast reconstructions were separated and reviewed. They were housed within three of the themes; *Being changed* (sub theme: 'physical changes'), *Being changed* (sub theme: 'not being changed'), *Control* (sub theme: 'being done to'), and *Normalisation* (sub theme: 'time heals'). Many of these comments related to the expected immediate and transient effects of radiotherapy, such as swelling, redness, pain or burning associated with this treatment. Some women mentioned a heavier and swollen breast while another said it became dry and flaky, but most reported this was relatively short-lived. There was also discussion about the gel or cream given to them to combat some of these treatment effects, although one mentioned the cream was helpful there were no other feelings expressed associated with using it. A participant alluded to having had a 'difficult' experience during radiotherapy, but that her memory recall meant she had

forgotten much of this. Others mentioned they were tired at the time, but this had since resolved. Longer-term effects were also discussed.

There were comments relating to the reconstructed breast being hard and a long-term effect that the texture of the breast had been altered. This the women attributed to radiotherapy, although there does not seem to be any negative emotion attached to these comments; they rather seem more statements of fact and understanding. It was also difficult to identify if comments about the reconstruction being lumpy and weighty are associated with the surgery, radiotherapy or the combination of these two modalities. Similarly, a participant detailed that she had a second procedure to fill a deficit that was identified on the reconstruction. However, once more this is not ascribed to a particular reason. The women were directly asked if they thought radiotherapy had any effect on their reconstruction. These responses contributed about a third of the comments housed within the 'not being changed' sub theme and were definite in their view. All eight participants who commented stated there were no effects from the radiotherapy, four did not embellish, but gave a categorical 'no'. This is a major finding of the research.

The published literature on the use of post-operative radiotherapy on TRAM/DIEP flap immediate breast reconstructions is contradictory and mostly related to the clinician's perspective. Literature has heavily debated this topic and, the choice of operation or order of treatment offered to women may differ not only depending on whether there is a need for adjuvant radiotherapy, but also, as there is no consensus, from one breast unit to another. Consistency in the recommendation of treatment plan cannot be guaranteed. In this research there were four comments from the participants that refer to their doctor's response to having radiotherapy post reconstruction. Views were split, as half of these four comments relayed a negative connotation. One participant felt her plastic surgeon was disappointed with the cosmetic results and one detailed her doctor attributing some reconstruction damage to the effects of radiotherapy. Two comments illustrated the opposite viewpoint: one suggested the medical team strongly

recommended this combination of treatment, while the other illustrated the surgeon, who had previously published on the disadvantages of post-operative radiotherapy, now held the opposite view. This conflicting information upholds the muddle that surrounds the research topic. It is likely the opinions of the healthcare professionals are sought by those undergoing these treatments, and it could be suggested that any addition to uncertainty or confusion would not be helpful for the patient or their decision-making process.

The research question related to the perceptions of the women in relation to the combination of TRAM/DIEP flap immediate breast reconstructions and post-operative radiotherapy. Much of the data collected, however, did not answer this question despite the use of a discussion guide that had been reviewed both by an expert panel and a user panel, the facilitator continuously reminding participants during all the groups that this was the focus of the study, and the researcher at the end of each of the group summarising issues stated regarding the combination of treatment and asking for any additional comment. Instead, the women discussed their breast cancer and experience. They shared tips and practical solutions discovered to other members within the groups. The participants did not separate the treatments, rather discussed their lived experience and issues that had happened to them. They did not specify which part of the treatment impacted them, rather discussed how their breast cancer treatment reverberated through every aspect of their life. The data do not seem to support the negative issues that are reported in other studies that detail implications of the combination of these treatments. The participants of this study appeared to minimise any effects and seemed comfortable with this order of treatment received, stating that they would recommend this to others who found themselves in a similar situation. Although longer-term issues are not known, the participants did not seem to have any issue with the specifics of post-operative radiotherapy on their autologous tissue breast reconstruction.

6.6 Issues with intimacy and body image

Breast cancer and the treatments involved may have extreme consequences in relation to sexual and intimate activities (Donnelly-Cairns 2011), and yet intimacy issues are traditionally one of the least discussed topics (Love 2000). Therefore, it was deemed particularly important to examine this within the groups. During this research, a number of the women discussed intimacy issues and sharing their new body with a partner. The findings do not illustrate that the participants in the main had experienced significant psychological trauma, or many consequences of this treatment on more intimate relationships. It seems the participants who were married had fewer issues with intimacy than those embarking on new relationships; some of the latter group appeared wary of sharing their bodies with new partners, and one participant had been delaying this for three years. This participant stated that the inability to share her breasts and be physical with her partner saddened her. Another participant who was single stated she would be wary and very conscious of showing a new partner her breasts. This was echoed by another participant in a separate group, although from a more positive point of view: she said she was sure she would find someone who respected the fact that this breast surgery would not impact their relationship. It appeared the seriousness of the relationship mattered to one participant, who discussed having shared her new body with partners and not really caring what they thought, yet she implied her actions would alter if she was in a relationship that she was more serious about, and that she would cover her breasts the first few times they were intimate.

In general, the women who were married did not share many thoughts and feelings about intimacy, rather they were more matter-of-fact, treating it as 'one of those things'. The resilience of the bond of marriage seemed to play a part here and any effects of the breast reconstruction on their physical relationships seemed minimised. Only one of the married women revealed her own perceptions of her husband's feelings: that he forgets about her reconstruction when he embraces her, and then, in her mind, she feels he slowly moves his hand away.

Although illness and treatment can interfere with sexual functioning, sexual interest, physiological sexual response and functioning (Crooks & Baur 2010), the comments that arose within the focus groups relating to intimacy were all associated with the emotions of the women and feelings they expressed relating to their body and body image. There was no comment about function or an alteration in their ability to perform these activities. There was some discussion about alteration in sensations and numbness experienced associated with their breast reconstruction, but no reference to dysfunction or pleasure experienced during intimate moments, which is possibly surprising given the intense surgery they all had experienced. Only one woman discussed her sexual appetite and desire when she commented on her and her husband's eagerness for her to be discharged post-operatively in order for them to resume this activity. In addition to their surgery, many of the participants had undergone chemotherapy and some were on endocrine treatment. Side effects of these modalities can include fatigue and menopausal symptoms, and yet, when the women were discussing intimacy or these other treatments, they did not refer to how they impacted on their sexuality or sexual function. Responses may have been different if the women had a mastectomy without reconstruction.

The women may need to achieve a level of self-intimacy prior to becoming intimate with others; that is, to accept their new body before they can become intimate and adapt to the alteration in body image. None of the participants mentioned feelings of their new body being faulty. Although numbness, pain and fatigue were experienced to some degree by the majority of the participants, the evidence suggests this did not have a large impact on activities of daily living; rather, they adjusted their lives in order to cope better. The women discussed being topless, and some participants now do not walk around the house topless, potentially illustrating body shame. Being topless on the beach was also discussed. A number of women stated they would not do this, although this was mainly associated with no desire to, as opposed to feeling unable to reveal their bodies in this way. There were also comments that relate to the women's age and that they might feel different about their breasts and perhaps more challenged as a female if they had

been younger. There was no discussion or conflict experienced by the women comparing their bodies to those of women who had not undergone the treatments.

Although Donnelly-Cairns (2011) state most women who have cancer are afraid of abandonment by their partners, none of the women spoke of feelings that related to this. Issues around sexuality and intimacy are, of course, multi-factorial and no information was shared about how the women acted within this domain prior to their diagnosis or treatment. In addition to this, there was no fixed response as to how couples behave when one is diagnosed with a potentially life-threatening disease and undergoes intensive treatment. Clearly some relationships can be strained, while it may bring others closer in a more open and honest way. Ussher *et al.* (2012) identified significant alterations in sexual well-being post breast cancer treatment, which were assigned to psychological and physical changes in the woman. Anderson (2009) reported that sexuality declines after initial diagnosis and treatment along with intercourse frequency, and that sexual satisfaction decreases from diagnosis and across five years.

Comments shared by the participants in this research about intimate relationships were largely encouraging. Although some detailed issues with body image resulting from this treatment, many others appeared to minimize the implications. In our society, breasts are considered part of femininity and desirability, and any scaring or loss of a part of the breast could cause detrimental emotional distress and a resulting loss of self-confidence (Gilbert *et al*. 2010). Through these focus groups, the women primarily illustrated resilience and a toughness in relation to this subject, and demonstrated there are few issues with sexual function itself despite having received such intensive treatment. The impact of cancer, treatment effects and the breast being part of what is traditionally deemed as sexually attractive do not appear to have caused severe alteration in this activity for these women at this time point post treatment. This may be due to the fact these women had an immediate autologous breast reconstruction as opposed to an implant reconstruction or no reconstruction.

Comments relating to intimacy and sexuality seemed to be free flowing within all the three focus groups and yet this topic was approached with caution and towards the end of the groups. This was in order the women felt more comfortable to discuss such issues.

6.7 The researcher's viewpoint

One of the reasons this work was commenced was to ensure patients who undergo these ambitious TRAM/DIEP flap breast reconstructions are prepared for the enormity of the surgery and consequences of treatment. Concerns about introducing bias to the groups in relation to the invasiveness of TRAM/DIEP flap reconstructions led to the decision to have an independent focus group facilitator (the Lead Research Supervisor) who had no knowledge of the topic. The value of doing this is borne out in the findings; participants did not voice concerns about the procedure.

6.8 The atmosphere of the focus groups

The constants across the three groups were the researcher, the facilitator, the setting and the discussion guide. Although each focus group was entirely separate and scheduled at different times on different days, the feeling and atmosphere of the groups were strikingly similar. The ambiance of the groups was informal and seemed light-hearted despite the topic material and serious nature of the content and conversation. There was much use of humour within all groups, and the women seemed to gel with one another, encouraging comment and freely sharing experience. The facilitator did not need to progress through the discussion guide by category, as conversation was abundant and advanced without the need for continual prompting. However, she did bring the group back to the topic periodically. When there were occasional lulls in the group's conversations, the facilitator would mention a topic from the guide not yet discussed, and this would result in conversations on this next topic. Each time the topics were mentioned, the facilitator reminded the groups that this was in relation to any effects from the combination of post-operative radiotherapy on their reconstructions. By the

end of each focus group, all issues on the topic guide had been discussed. The women did not need much encouragement to disclose information on the shape of their breasts, their thoughts surrounding this, friends, family, intimacy issues, or any physical, psychological or social implications of their breast cancer experience. The conversations were of an incredibly sensitive nature, which could have engendered a sense of vulnerability, and yet the tone of the groups was almost social in nature. The women had all experienced two of the same treatment modalities, thus shared experience resulted; there was an incredible sense of compassion and kind-heartedness among all participants. The women appeared extremely open to discussing their encounters in addition to being respectful of everyone's opinion, giving each other time to talk without interruption.

6.9 The bigger picture; the breast cancer experience

The participants spoke in detail about their breast cancer experience. Therefore, a literature search was performed to identify other qualitative literature about this subject, with a view to reflecting on how findings of this study compare and contrast with published research. To this end, breast cancer, meta-synthesis, systematic review and qualitative research were input into the search engines Medline, Embase and PsycInfo, yielding three reviews of breast cancer experience (Appendix 7). These were studied after the focus groups and data analysis took place so as not to biased or influence interpretation of the data.

6.9.1 Introduction of the three qualitative reviews

The three meta-synthesis reviews were all published in peer-reviewed journals (Arman & Rehnsfeldt 2003, Bertero & Chamberlain Wilmoth 2007, Denieffe & Gooney 2011).

Arman & Rehnsfeldt (2003) aimed to review qualitative or mixed method studies published between 1990 and 2000 pertaining to the lived experience of those with breast cancer, interpreting it within the viewpoint of suffering. Fourteen articles were examined and categorized into eight 'concepts'. This

meta-synthesis concentrated on suffering from an emotional vantage point with no mention of the physical suffering people with breast cancer experience. This review was not straightforward to read as, rather than summarise the literature, it detailed many of the individual papers, which did not result in cohesive writing.

Bertero & Chamberlain Wilmoth (2007) identified 30 articles in their meta-synthesis, and reviewed qualitative research from 1990 to 2003 on the treatment of breast cancer and how this affected the Self. They identified four aspects in the literature and, perhaps surprisingly given that they shared a decade in their search strategy, there was only an overlap of two studies from those detailed within the Arman & Rehnsfeldt (2003) meta-synthesis where breast cancer and suffering was the focus. This work is clear, and signposting within it results in an interconnected and organised paper.

Denieffe & Gooney (2011) concentrate their search on women's symptoms experienced from diagnosis of breast cancer to the completion of treatment with no timeline exclusion. This analysis includes 31 studies, distilled within four themes. There were no papers that overlapped between this work and Arman & Rehnsfeldt (2003), and only five that overlapped with Bertero & Chamberlain Wilmoth (2007) despite the second two meta-syntheses both alluding to breast cancer having effects on the Self. As with the other meta-syntheses, Denieffe & Gooney (2011) use a table to summarise the individual articles they reviewed, which allows information such as the author, publication year and methodological orientation to be seen. However, while the other two have a column for the major findings, which provides a useful resource, this analysis does not. Instead, the authors have chosen to construct a second table illustrating their own themes and have listed the articles under these. Denieffe & Gooney (2011) do, however, detail sample size, treatment, country of origin of the study and, where identifiable, the timeframe that the women in each article were post diagnosis, which is useful when reading this paper. Twelve of the 31 studies reviewed included information that related to women who were at least one-year post diagnosis.

Table 6.1 illustrates the matrix of themes identified within the present research and the three meta-synthesis.

Table 6.1 Themes and concepts identified in current study and related meta-syntheses.

Identified themes and concepts			
This study	**Arman & Rehnsfeldt (2003)**	**Bertero & Chamberlain Wilmoth (2007)**	**Denieffe & Gooney (2011)**
Being changed	The Initial Stage of the Breast Cancer Experience	Awareness of One's Own Mortality	Breast Cancer and the Impact on Self
Control	The Body and Breast Cancer	Living With an Uncertain Certainty	Self-Image and Stigma
Coping Strategies	Suffering	Attachment Validation	Self and Self-Control
Information	A Turning Point	Redefinition of the Self	More than Just a Symptom
Normalisation	The Concept of "Changes" in Connection to Life Orientation		
Trust/Faith in Healthcare Professions	Interpersonal Dependency		
	Transition, Transformation, and Finding Meaning		
	To Reach Transformation or Not?		

6.9.2 Discussion of study findings in relation to qualitative meta-synthesis

The six themes identified in this research will be explored and these will be examined in relation to the findings of the three meta-syntheses, identifying if themes are echoed or if there is discordance. There will then be a section on themes identified within the meta-syntheses that were not evident in my research and vice versa.

6.9.2.1 Being changed

The five sub-themes identified within this theme of 'physical changes', 'relationship changes', 'behavioural changes', 'psychological changes', and 'not being changed', will be discussed under the umbrella theme *Being*

changed. These were the lasting effects of having breast cancer and cancer treatment, and included physical and psychosocial implications.

Despite 'The body and breast cancer' being a theme used by Arman & Rehnsfeldt (2003), little information is held within this section and they commented that findings within the literature were contradictory and complicated without giving explicit examples. It appears that some women appeared to embrace their altered bodies and being, while the authors detailed there were a number of studies which did not mention the effect this disease had on the woman's bodies.

In my study, the participants seemed on the whole to be accepting of their changed bodies both physically and psychologically. My research contained detail regarding how the women felt and actual physical sensations experienced, for example, numbness or hot flushes that resulted from treatment. Denieffe & Gooney (2010) mention within two of their themes physical, social and psychological indications when the Self was affected by breast cancer treatment. Although they listed the individual symptoms of pain, fatigue, skin changes, and smell and taste changes diagrammatically, they do not mention them further. My findings elaborate on these issues and what the women felt about these. What the review does detail is that symptoms experienced physically by women such as hair loss, menopausal issues, weight gain and sexual problems impact the woman psychologically, which affects the Self.

Despite Arman & Rehnsfeldt (2003) concentrating on 'suffering' experienced post breast cancer diagnosis, and labelling one of their concepts as such, it is the shortest concept in their work and one where no detail is given about physical suffering. Although the participants in my research mentioned pain and arm function issues, they did not dwell on suffering, but rather were relatively upbeat and factual when relating to their experiences.

Arman & Rehnsfeldt (2003) give no description of specifics that relate to the breast being changed or explicit consequences treatment has had on the

women's bodies apart from that this has an impact. While Denieffe & Gooney (2010) identify the breast as symbolic of femininity and womanliness, it is a brief section, and one which implies how the aberrations women have as a consequence of breast cancer treatment result in a cognisance which may alter their Self and how they feel identified by others.

In my study, despite being mentioned in the discussion guide, the issue of body image was not deliberated at great length; it could be seen as reassuring that other studies also do not mention this to any extent, perhaps implying an inner acceptance and resilience from the women.

In their concept 'redefinition of self', Bertero & Chamberlain Wilmoth (2007) relate to the emotional and physical aspects of life post diagnosis and treatment, and this is contained within three threads: 'body picturing', 'physical functioning' and 'womanhood/femaleness'. As one might expect, the 'body picturing' subdivision contains within it issues that concern the women in the studies not feeling 'normal'. 'Normal' women in this case were those with two breasts and who had not experienced wider physical issues that can result post breast cancer treatment, for example, hair loss. There is no mention of breast reconstructions within this review, or any detail as to whether having a reconstruction 'allowed' women to feel more 'normal' if the breast mound was reinstated, although it is reasonable to suggest that some of the sample within the studies reviewed would have undergone this surgery when noting the years the research was undertaken.

This review found that darker skinned women (Asian or African) were conscious if they had lighter-toned breast prostheses post mastectomy and this, partnered with other thoughts of not identifying with their own 'new' bodies, affected the Self. Although some women post breast reconstruction chose to wear breast prosthesis in order to improve symmetry, none of the participants in my research did. Denieffe & Gooney (2010) also mention post-treatment body changes and state these alter the person's thoughts of themselves, how they imagine they are viewed by others and that these 'new bodies' separate them from normal people and stigmatise them. Although

there was discussion regarding being different, there was no evidence of not feeling normal within my focus group discussions, although some of my participants suggested that they would no longer go topless on the beach or around the house, but this was not explicitly related to not feeling normal.

Denieffe & Gooney (2010) mention feelings the women had in relation to their bodies being broken: that they felt let down by them and were 'discredited' by having cancer, which led to a feeling of inadequacy and a dichotomy between wanting to recover their bodies and yet identifying them as an adversary because they felt betrayed by them. This was not identified in my work.

The 'different physical' sub-theme in my study illustrated additional concerns or aspects of this which is missing from the meta-analysis and encompasses consequences of not feeling normal, or appreciating their bodies were now different. This was in relation to wearing different bras, (at least in the immediate post-operative setting), altering behaviour so as to follow lymphoedema prevention advice and tips used to combat hot flushes experienced post treatment. This information can be used and disseminated to advantage others and equip them with valuable, constructive information.

There is a shared theme within my research and in the meta-syntheses of women wishing to review their lives. Arman & Rehnsfeldt (2003) use their concept 'A Turning Point', Berto & Chamberlain Wilmoth (2007), the 'Awareness of one's own mortality' and Denieffe & Gooney (2010), 'Breast cancer and impact on self' to detail how some participants reviewed their lives by changing aspects, setting goals and reprioritising their time. One of the participants in my study completely altered the path of her career, moving from someone driven by work (a self-admitted 'workaholic'), to someone now in training to become a life coach.

'The concept of "changes" in connection to life orientation' was one identified by Arman & Rehnsfeldt (2003) and here additional comments sit relating to reprioritising life and focus. These issues are echoed in my research and,

once again, can be illustrated by the participant who resigned from her job and decided on a new vocation. Other women in my study mentioned being healthier, allowing more time, reprioritising relationships, reducing their inhibitions and an ability to shape a newer, stronger identity. An 'inner power', reconciliation and redefinition is mentioned by Denieffe & Gooney (2010), which appears to support these findings, although they infer that, to the woman, life will never be the same again.

Bertero & Chamberlain Wilmoth (2007) mention practical ability in respect to frustration when some are not able to complete household chores as previously. Denieffe & Gooney (2010) identified a theme of 'self and self-control', which describes a lack of function that some women experienced and, although the specifics are not mentioned, the women fall short of their own expectations. This could be similar to the fatigue experienced by many participants in my study. In fact, Denieffe & Gooney (2010) state some wished to control fatigue in order to maintain their integrity and control. The physical functioning thread identified by Bertero & Chamberlain Wilmoth (2007) detail a negative impact on the Self and that the women assigned a reduced value to themselves because they could no longer perform tasks as before. This is not seen within my study as, although mentioned, the women discussed tips they had adopted and built into their routines in order to carry out individual activities: for example, having naps to combat fatigue. A participant did mention that she was no longer able to take her fencing class due to the risk of her developing lymphoedema, but this was stated in a matter-of-fact manner as opposed to being detrimental to how she saw herself.

Arman & Rehnsfeldt (2003) segregated the literature within their 'suffering' concept and listed what each of the four papers mention: pain, loss, transcendence and a threat to life itself. In addition, they mention how suffering links with the woman's spiritual life. In my study, there was only one mention of faith, and this was in relation to the participant developing a stronger faith and maturity post breast cancer experience. Bertero & Chamberlain Wilmoth (2007) also mention spirituality and God as important,

as this delivered a value to the women's lives, providing them with strength for the situation they faced. There is no mention of this by Denieffe & Gooney (2010).

Changing relationships the women had within my research took many forms. Some detailed a closeness, while others commented on the anger and avoidance that they experienced from friends and family. Some shared their experience and some were private, choosing whom to disclose feelings to, while others commented on how family and friends showed support by attending appointments with them. The women felt they have become closer to some people while more distant from others.

'Interpersonal dependency' was another category identified by Arman & Rehnsfeldt (2003), and this briefly detailed alterations in personal relationships although it does not state where the women received support from or whom they chose to undertake this activity. Despite slight overlap in their 'attachment validation' aspect, Bertero & Chamberlain Wilmoth (2007) frame this not only within family, but also to a person's significant other, in addition to healthcare professionals. They commented it was vital the women considered themselves to be valuable to these people and to their lives.

The detail Bertero & Chamberlain Wilmoth (2007) report that relates to the woman's significant other is in relation to a validation they felt when they were accompanied by them to appointments and when love was bestowed upon them. This took the form of emotional and physical activity, and it seemed the women found it important to feel cared for as an individual as opposed to someone with asymmetrical breasts. As with my research, these authors described women wanting to protect some family members from the truth, and the authors stated that there are negative effects on the Self if they felt someone was evading the individual concerned. One participant in my study spoke of a relationship breakdown with her sister and another of the jealousy a sibling felt due to the improved relationship with her brother as a consequence of having breast cancer. Neither Bertero & Chamberlain Wilmoth (2007) nor Denieffe & Gooney (2010) illustrated a strengthening of

relationships as seen in my study; in fact, Denieffe & Gooney (2010) detail some received a negative response from friends on hearing about the cancer diagnosis, followed by alienation.

Arman & Rehnsfeldt (2003) and Bertero & Chamberlain Wilmoth (2007) reaffirm detail found within my research regarding being honest with children and the importance of how the child positively interacted with them. Denieffe & Gooney (2010) mention motherhood as something that can be drawn from to stabilise clashing dynamics, and to gain meaning and carry on with life.

Arman and Rehnsfeldt (2003), and Denieffe and Gooney (2010) do not detail issues regarding intimacy or any particular mention of partners, whereas this was a domain within the focus group discussion guide and one deemed important to gauge opinion. Bertero and Chamberlain Wilmoth (2007) mentioned single women in the literature they reviewed and stated these women were anxious about remaining single, as their post-treatment bodies might reduce their ability to find a new partner.

These are similar to the issues discussed in my research where single women appeared to have more issues relating to sharing their altered bodies in intimate situations. One participant was worried about showing her body to her partner, and another spoke of fears she might have revealing her body if she truly cared for someone, despite having fewer anxieties associated with more casual partners she had been intimate with post treatment.

Bertero & Chamberlain Wilmoth (2007) capture comments related to the women worrying they may no longer be desirable or loveable, and some wondered if they could still be classed 'a woman' despite not looking like one and the difference they feel it had sexually. These are sober statements and compound the comment within the focus group of someone wishing to be upfront with her partner rather than *'pretend that nothing is lurking underneath'* (F2:P7:L793). Humour was also used in this setting within the focus groups, perhaps in a way to dispel the seriousness of the discussion.

Bertero & Chamberlain Wilmoth (2007) do mention responses to sexual activity and that some felt inhibited while others felt their bodies reacted differently and, although orgasm was still experienced and it was 'good', it was different. They also mentioned that emotion and pleasure from intimacy were changed, but do not state if this activity was in an established relationship or ones formed post breast cancer diagnosis. Although intimacy was discussed at considerable length in my study, the participant's ability to orgasm was not.

In addition to the findings of these meta-syntheses, my study also contains physical issues that women post treatment experienced both at the time of and after treatment was completed, for example, pain experienced or issues with their arm. Lasting physical implications were discussed by the participants along with recommendations they had for women who found themselves in a similar situation.

6.9.2.2 Control

This second theme identified in my study contains the sub-themes 'being done to', 'treatment', 'fear of cancer', 'no control', 'taking control' and 'disclosing'.

Arman & Rehnsfeldt (2003) and Bertero & Chamberlain Wilmoth (2007) dedicate their first concepts to themes relating to the 'initial stage of the breast cancer experience' and an 'awareness of one's own mortality'. Feelings of shock, trauma, uncertainty and despair were characteristic within the literature, as was a mention of the women trying to make sense of their new situation. A diagnosis of breast cancer has implications on thoughts, and this was echoed in my study where a number of participants discussed the shock and surreal nature of being diagnosed. These participants also discussed how follow-up tests made them anxious and the thought that another cancer would be detected; this is not identified within any of the meta-syntheses. Bertero & Chamberlain Wilmoth (2007) do mention a 'shadow of doubt' that women experienced along with being labelled from

that point forth as a breast cancer patient and Denieffe & Gooney (2010) mention a stigma that having breast cancer brings. Arman & Rehnsfeldt (2003) stated women diagnosed with breast cancer need to obtain strength and verification in a protected, secure and sympathetic setting, which may have taken place for the participants in my research.

Although taking control is mentioned by both Bertero & Chamberlain Wilmoth (2007) and Denieffe & Gooney (2010), the authors do not detail how these women were striving to achieve this. My work gives examples such as women shaving their hair off, participating in trials and making decisions about their care as ways they took control. Denieffe & Gooney (2011) briefly discuss decision making, and state that, although the women in the studies they reviewed wanted to do this, it was accompanied by confounding thoughts which resulted in them worrying whether they had made the correct choices. Some of the women in my focus groups had undergone pre-operative chemotherapy and so may have had longer to discuss their extensive surgery, which could have enabled them to feel more at ease with decisions made.

Choosing whom to tell about their cancer treatment was discussed within my groups and the women seemed to divulge what they wanted to whom they wanted. Denieffe & Gooney (2010) also documented that women in their review cautiously selected who they informed about their cancer, although the reason proposed for this had more to do with avoiding any horror they might get in response, as opposed to the more empowering reason of control identified in my research. There are no other mentions of any relationships, either family, significant others or friends, from these authors; rather they concentrated on differences that being diagnosed and treated for breast cancer has on the Self.

Although Denieffe & Gooney (2010) summarised that women wished to remain in control, independent and capable, my research delivers additional rich detail in relation to the control women felt they either had or did not have, in addition to a more comprehensive outline of the coping strategies and self-supportive activities that they undertook, such as post-operative arm

exercises. My research also makes reference to breast cancer being in the media: many of the participants described annoyance at seeing charity pleas for money or articles in newspapers or magazines, as this reminded them of their experiences. Other roles apart from the fundraising aim of charities are not discussed within any of the literature nor in my research. These roles could have taken the form of additional information leaflets or helplines that the women may have found of use.

6.9.2.3 Coping strategies

This theme of my research had within it the sub-themes 'physical adjustments', 'being positive', 'deflecting', 'self-management' and 'support'.

Arman & Rehnsfeldt (2003) used 'a turning point' as a concept for their literature. Within this section there is detail of the women in the 14 studies they reviewed altering their outlook from the 'why me' to 'why not me', and a narrative of a more positive frame of mind and adapting to life. In my research, there was no mention of 'why me' or 'why not me', rather almost an acceptance that followed after the shock of diagnosis and the treatment. The positive outlook was present within the focus groups and humour was used at points, in addition to a 'feistiness' displayed by some of the women being unapologetic about their bodies and attitudes to situations. It is not clear how long after diagnosis these 14 studies took place and, although they may have been at various different points, it would be reasonable to suggest that the 'why me' mental state may have been experienced by the women in my research within the first year post treatment and they may have travelled through those previous transient thoughts if they ever experienced them.

Although there is a brief mention in the work by Arman & Rehnsfeldt (2003) of the women assisting others and receiving help themselves, it is not detailed from where this help heralds. Bertero & Chamberlain Wilmoth (2007) give similar reference to support, stating it was of benefit and, although they add both practical and emotional support was welcomed, it is unclear if this was from healthcare professionals, other women, or friends and family.

My research gives more detail in relation to support, as this is a sub-theme split into the two meanings of 'support from others' and 'supported by other patients'. Both my research and these meta-syntheses describe it was supportive to discuss issues with someone who has experienced breast cancer as this gave hope, although the scenario where this support was given is not mentioned. There is a participant in my research who stated that she would not wish 'to sit around and chat about *her* cancer' while another stated this support mechanism had helped.

In addition to this, this theme illustrated coping strategies adopted by some in order to combat any effects of treatment: for example, using their arm differently or wearing a soft bra during the post-operative period. There was also much regarding being positive, which included comments that related to having a flatter stomach post reconstruction and also some being pleased they had received their chemotherapy pre-operatively when they felt at their strongest. Noticing milestones in the treatment, such as chemotherapy being completed, was mentioned as a coping strategy and a way to focus on what had been achieved and what was yet to come.

Issues relating to self-management were also discussed, such as where specific arm exercises would be undertaken, and this seemed to be from an empowering vantage point. Many of the women also spoke of 'worse things', and these referred to issues such as dying from breast cancer, that their experience may have more intense implications had they been younger in age at diagnosis, and to stories they had heard regarding other people's inferior experiences at other Trusts. Implant breast reconstructions were also mentioned here, and there appeared to be a shared relief among these women that they had been offered an autologous breast reconstruction as opposed to an implant-based reconstruction. The women appeared to suggest the autologous reconstructions were superior, which may be due to a number of factors, including associations they may have relating to past negative media publicity about poor quality products. Relief was also apparent when the groups discussed being cared for by the team who were responsible for them.

6.9.2.4 Information

This theme had three sub themes within it; 'good information', 'poor information', and 'would recommend.'

In their 'Living with an uncertain certainty' concept, Bertero & Chamberlain Wilmoth (2007) made one reference to information received and state this was a benefit to the women, allowing them to reduce uncertainty and prepare for treatment. None of the meta-syntheses detail if the women in the studies commented on whether information was good or bad; neither do they illustrate if women sourced additional information for themselves, which they did in my focus groups.

The women in my study readily shared an eagerness to assist others who found themselves in a similar situation with decision-making. Although this is echoed by Arman & Rehnsfeldt (2003), where they identified an awareness and readiness to help others, it is not mentioned in either of the other meta-syntheses.

This theme discusses poor information given and some identified a bombardment of information upon diagnosis which resulted in them not being able to digest all they were told. Chemotherapy, lymphoedema and some aspects of the post-operative experience, such as the bandages they would experience, were mentioned specifically in relation to poor information where some participants did not remember what they had been told. That being the case, the majority of women would recommend this combination of treatment to other women faced with this situation.

6.9.2.5 Normalisation

Sub-themes within my *Normalisation* theme were 'acceptance', 'getting on with life', 'more normal', 'new normal', and 'time heals'.

Within their concept, 'A Turning Point', Arman & Rehnsfeldt (2003) seemed to endorse findings that relate to the women almost finding peace and

meaning with who they are post treatment, which spurs them on to initiate adjustments in their lives. Their literature review also alludes to some women who appeared to be stuck or possibly paralysed by their cancer experience, showing no signs of moving to their turning point. This was not evident in my findings and may reflect the amount of time that the women had lived post breast cancer diagnosis.

Another concept identified by Arman & Rehnsfeldt (2003) was 'transition, transformation and finding meaning', where issues such as 'acceptance', 'the new normal', 'getting on with life', 'self-healing' and others similar to those found in this 'normalisation' theme are noted. It seems this concept related to the women making sense of the experience, healing emotionally, gaining self-esteem and adjusting after this episode. Denieffe & Gooney (2010) mention similar ideas in which the women needed to find meaning in order to release suffering and achieve self-transformation.

The overwhelming resilience women appear to have post breast cancer experience is illustrated in my research as, at the time of the focus groups, the participants appeared to have found an acceptance of what they had been through, along with the lasting consequences of the treatment they received. This is mirrored in the category 'to reach transformation or not' (Arman & Rehnsfeldt 2003). Here, there is discussion and detail about variation that the women in the literature showed in finding acceptance of their experience; they detail some seem unable to do this and, while the majority concentrate on positive changes, others drift from one level of transformation to another.

Bertero & Chamberlain Wilmoth (2007) did not include any information that links with this theme as, although they used 'redefinition of Self' as a concept and there is mention of the women acknowledging they were different from 'normal' women, the literature related this to feelings of imperfection, and concentrated on negative aspects of activities they were unable to perform. Despite reference to the women acknowledging their physical changes, it appeared they still grappled with redefining the Self. The work focused on

effects breast cancer had on the Self and, although detailed, the essence of this paper appeared to concentrate on differences felt, worries regarding uncertainty, and that being loved and respected was important. There is no mention of feeling positive or empowered.

The participants in the focus groups give examples of their empowerment and acceptance of their new bodies. One stated she still wore clothes that could reveal scars and said simply that, if anyone asked what had happened, she would tell them.

6.9.2.6 Trust/faith in healthcare professionals

Three sub-themes of 'good care', 'poor care', and 'trust professionals' were identified within this theme.

My research detailed feelings participants had towards specific healthcare professionals they interacted with, where these interactions took place and the information they received. Praise for the healthcare team came from 12 of the participants, and this related to decision-making support, care received and how the team had worked as a whole. Poor care related to practical aspects of receiving radiotherapy, having a mammogram and some features of post-operative care. There also seemed to be a reluctance to cease follow-up appointments as, although these were accompanied with fear that the cancer had returned, the women enjoyed and felt reassured when they were reviewed by their doctors within the hospital setting and a sense of abandonment appeared once these appointments were no longer required. This finding supports detail that can be added to the pre-assessment and post-operative consultations, in addition to the patient information leaflets used within the clinical setting in the hope of improving patient experience.

Bertero & Chamberlain Wilmoth (2007) discussed the part healthcare professionals play for these women, and suggested the women had an overwhelming wish to be treated as an individual with respect and to take part in any decision-making about their treatment. This is also seen in the

work by Denieffe & Gooney (2011) where they state that, although healthcare professionals gave opportunities to be involved in decision-making, the women felt out of control and rushed, as these decisions occurred while they were attempting to absorb their new diagnosis. The women in the focus groups extensively discussed their relationships with healthcare professionals and decision making, which differed from the Denieffe & Gooney (2011) study, as they stated they did not feel rushed or overwhelmed despite the extent of the surgery they were to have. The meta-syntheses did not inform the reader what treatment women received in the articles they reviewed, but it is unlikely they all underwent these ambitious immediate breast reconstructions as the women in my focus groups did. The women in the focus groups appeared satisfied with the autonomy they had in regards to decision making and also said they received individualised care for which they were grateful. They detailed a trust they had for the team and feelings of security that wavered slightly when they are discharged from hospital care.

Unlike in my research, individual cadres of healthcare professionals are not specifically identified in the meta-syntheses, nor is if the women actually experienced the validation and respect they sought from the team.

6.9.2.7 Themes identified in meta-syntheses but not in this study

Bertero & Chamberlain Wilmoth (2007) mentioned fertility and specifically that younger woman who had experienced a treatment-induced premature menopause worried they were incomplete. While one of the participants in my study was 35 years old, and another four were under 50 years (the average age for a natural menopause), fertility or issues relating to a lack of fertility were not discussed. The youngest women in my study did not mention children.

6.9.3 Summary of Arman & Rehnsfeldt (2003)

This meta-synthesis concentrated on the emotional and psychological aspects of a woman having had breast cancer from the perspective of suffering, but does not discuss any physical or lasting effects of treatment.

Relationships are mentioned, but these are ambiguous and could be associated with friends, family or partners, and there is no precise information associated with partners or issues regarding intimacy. Specific individual treatments and associated feelings are also not examined; more the thoughts and feelings associated with the disease and its treatment.

6.9.4 Summary of Bertero & Chamberlain Wilmoth (2007)

This meta-synthesis focused on the evidence that qualitative research provided in relation to the effects breast cancer and its treatments have on Self. Once more the emotional impact of the diagnosis is explored, as is 'living with uncertain certainty.' Although the authors reported that information and support (both practical and emotional) reduced uncertainty and stated talking to a breast cancer survivor is a positive experience, they did not otherwise elaborate upon their views of what form useful information or support takes. Although some detail is provided relating to the women's new bodies and lasting implications of treatment, this is limited.

6.9.5 Summary of Denieffe & Gooney (2011)

The emphasis of this work related to the symptoms experienced by women from breast cancer diagnosis until the end of their treatment. This meta-synthesis concentrated on the impact a breast cancer diagnosis had, in addition to stigma felt. Although there is mention of reprioritising life, it is downbeat, giving reference to life never being the same again as the Self has been radically altered. These women felt let down by their bodies and there is a battle regarding control, illustrated by the need to make decisions about their treatment, and yet this prompting feelings of bewilderment. The authors did mention individual symptoms that are the result of breast cancer and its treatment, and how this negatively affected them psychologically.

6.9.6 Summary of additions to knowledge from the focus groups

The meta-syntheses did not directly communicate with women in their work, rather they relied on data supplied by the studies they included, and each individual paper may have author bias or include different approaches

depending on which country the research was conducted in. The focus groups allowed direct access to the women.

This research discusses physical, social and psychological issues, in addition to delivering more data in relation to feelings towards the healthcare team, breast cancer in the media, coping strategies adopted, control and information given. The effects of treatments are also discussed at a greater length illustrated, for example, when the participants discussed the immediate effects of radiotherapy or side effects of endocrine treatment. These additions to knowledge allow healthcare professionals to gain more of an understanding about the experience of breast cancer and associated treatment. This additional information can be used to respond to issues raised and can provide a framework, allowing appropriate, practical help and support to be offered to these women in the future. The aim of this would be to improve the patient experience and approach the specific needs of this group of patients in a more holistic manner.

The women in my groups appeared to have a more positive outlook and used humour a number of times during conversation. There seemed to be a different atmosphere within the focus groups than in the meta-syntheses; the participants gave the impression of being more empowered and positive despite the experiences and treatment they had undergone. The reviews give a bleak and negative view of a woman's breast cancer encounter, especially the meta-synthesis authored by Arman & Rehnsfeldt (2003). Bertero & Chamberlain Wilmoth (2007), use similar timelines for studies they included, so it could be suggested there have been improvements that have occurred in more recent years that relate to the delivery of treatment and care that impact on the experience of women with breast cancer. Denieffe & Gooney (2011), do not restrict their review by year of study, but despite this there is also much negative content, for example the women feeling let down by their bodies and stigmatised.

6.9.7 Reflections on meta-synthesis – interpretation

Interestingly Arman & Rehnsfeldt (2003) conclude that the women's experiences may have been interpreted in a reduced way, possibly due to the researchers' own evasion of the bleaker aspects of the experience or as a result of the nurse or researcher not wishing to accept these facets, as they oppose the emphasis of nursing as supporting and caring for patients. I have mentioned a number of times that the participants of the research appeared to minimise much of their treatment and any resultant issues they experienced regarding post-operative radiotherapy. I reflected on this and the thought process that accompanies this statement in addition to reviewing the data, but do not think my interpretation was affected in this way. The focus groups gave ample opportunity for participants to discuss darker issues more extensively and yet, despite this, comments within the 'fear of cancer' sub-theme remained relatively brief.

6.10 The use of numbers within this study

Focus groups were the method chosen for this research as I thought it most useful in order to extract what women thought and felt about their breast cancer treatment. This resulted in many comments that were divided into themes, sub-themes and meanings. The findings chapter held much reference to the number of participants who had commented on each of these particular themes, sub-themes or meanings as I deemed this valuable and a faithful way to report the raw data. I felt it was important in acknowledging the comments from the women and added a different dimension to the findings, while adding emphasis to the statements. The study examined the shared experience of three small groups of participants and this is what the inclusion of these numbers highlights; eight people saying the same thing is as important as only one, but in identifying how many said what allows the women's shared thoughts to be taken into account.

6.11 Reflection

As previously alluded to, apart from possible irritation being experienced by the participants from charity fundraising efforts, the women did not mention the breast cancer charities, of which there are many. These charities not only fundraise but also provide an information service in addition to a free telephone help and support line. None of the women mentioned this or if they had used these charities throughout or after their treatment, nor did they discuss if the information booklets they must have received that were written by these charities were useful.

6.12 The cancer Clinical Nurse Specialist

One omission in the findings of this study is perhaps the lack of mention of the Clinical Nurse Specialist (CNS). Although the participants discuss support they received from healthcare professionals, these nurses are not mentioned per se. Support from nurses on the surgical ward and doctors (both breast surgeons and plastic surgeons) is mentioned, but not the CNS under any of their other possible job titles; key worker, specialist nurse or breast care nurse.

The Cancer Reform Strategy (DH 2007) illustrated the importance of the cancer CNS, detailing this role as pivotal and vital to patient outcomes, as timely interventions provided by this cadre of nurses can deflect expensive care episodes (Vidall *et al.* 2011). There is evidence that supports those with cancer who are undergoing treatment at hospitals with more CNSs have a better experience, as they receive appropriate emotional care. They also report the healthcare professionals in charge of their care worked well as a team (Griffiths *et al.* 2013).

The CNS in breast care are responsible for providing information and support to patients throughout their breast cancer trajectory. These nurses are introduced to the patient on their diagnosis of cancer, and their role encompasses assisting with decision-making regarding treatment. There can

be much discussion regarding treatment options between the patient, their family and the nurse.

The focus of the role of the CNS is to provide information, support and coordination of care for the patient and their families, and they are the first point of contact for the patient while they are receiving treatment or afterwards when they are in the community. Despite the evidence illustrating that these nurses play an essential role in the care of people with cancer, they were not mentioned by the participants in this study. One wonders if the participants may have mixed them up with ward or outpatient nurses, although it would be unlikely for all participants to have done this. At the Trust where I work and where this research was undertaken, it is a requirement for a CNS to be present when a person is given a cancer diagnosis, and the relationship between patient and nurse commences from that touch point. The research does not provide any evidence of this. It is likely that much discussion took place regarding this extensive surgical treatment and these participants would also have engaged in an additional step, as they would have had an extra outpatient appointment with the plastic surgeon. It is assumed the CNS would not only have attended these appointments, but also coordinated them while providing information and support. The CNS may have also reviewed the participant while they were in hospital for their operation. This would be in order to identify any unmet need or consequences of treatment, and refer on as necessary to other healthcare professionals or additional sources of support. These women, in the main, had undergone extended treatment which included chemotherapy and so may also have had the CNS complete any Macmillan charity grant forms or similar.

A potential reason for the CNS not being mentioned may be that, during chemotherapy treatment, nurses who work within the chemotherapy unit oversee the participant's care and become the key worker. The participants would have also been reviewed by a CNS who specialises in plastic surgery both pre- and post-surgery in addition to having appointments at her dressings clinic. None of this was mentioned, and perhaps the participants

identified this nurse as an outpatients' nurse as opposed to a dedicated nurse who is allocated this responsibility. The women would have also had interactions with the nurses and radiographers who work within the radiotherapy department. Perhaps, as there is such a raft of healthcare workers and nurses who input into a woman's care while she is on this trajectory of treatment, it is difficult to decipher who is who. There were no comments that support was lacking, so wherever the participants received their support and information from, this appeared to be at the correct level of detail.

One interpretation of no mention of the CNS could be that, although they were the linchpin and in the background, the nurses did not create a dependency. It seems the CNS team was taken for granted, as the pathway these women experienced worked. There were no issues mentioned regarding a lack of coordination of care, and the information given matched the needs. This could hallmark the skill of the team and be illustrative of them working to a high standard and delivering professional care.

6.13 Strengths of the study

This study's response rate was good; 25 of the 30 identified sample responded in some way. Thus it could be suggested the participant information sheet sent out to them was understandable and contained relevant information. All those who agreed to attend a group, turned up, and the discussions kept to time and on focus. The reimbursement of travel fares and voucher may have made the women feel more valued and that their comments and the experience shared were more appreciated. Hosting the groups at a cancer support centre kept the environment non-clinical, and the use of an experienced facilitator gave the researcher confidence that the discussion guide would be followed and that there would be ample and appropriate probing of relevant issues.

The addition of the 'user panel' and 'expert panel' added a rigor to the study. Despite the discussion guide being shown to both a mix of the breast multi-disciplinary team and to service users, only one adjustment was required.

The demographic data collected at the beginning of each focus group illustrated a wide representation of ethnic groups within the participants, adding richness within the data and illustrating any cultural differences. However, no major differences between women of different origins was apparent during the groups. The age range of the sample was wide (spanning from 35 years to 74 years old), and there was a good mix of those in employment or in other work situations.

6.14 Limitations of the study

The combination of this surgery and radiotherapy is relatively rare so the sample size is relatively small, although, in qualitative research the richness of the data is considered most important and in this study much data was produced and it is believed that saturation of data was achieved, as no new themes appeared to emerge.

A possible limitation is that the participants were accrued from one site and not multiple sites spread over wider geographic boundaries. This is a limitation because there may be differences in experiences from patients who received treatment from other units. Instead, all the women received their treatment from one hospital, although some were diagnosed at another Trust and treated at this Trust through tertiary referral. There is, therefore, no way of comparing women's experience from other breast units and if these would be similar or not.

Through the use of focus groups, the researcher was able to gain the viewpoints of a number of women collectively, and the women were able to share experience and prompt each other during the session. A possible limitation of this method is that perhaps some participants felt unable to share in-depth or more emotional or personal experiences. One-to-one interviews

might combat the privacy issues, although the focus groups produced good discussion regarding intimacy and relationships, and most members engaged in these discussions.

Selection bias may be a limitation to this study, as the dates and times of the groups were decided on according to possible access to the venue, in addition to the availability of the focus group facilitator. Although these groups included many of the women who responded, there were some who were not able to attend any of the three groups.

A possible limitation of the study was the response rate of the 'expert panel'. Out of the selected group, five of the 11 responded despite the request and associated timeline. A possible reason for this may have been that the researcher had only just joined that hospital site and therefore some of the clinical team did not know her or have enough introduction to the request.

The participants may have felt they needed to please the clinical team who provided their care, and an attempt was made to combat this by the nurse researcher not having had any association with them while this combination of treatment was being delivered. In addition, the use of a focus group facilitator who had no connection to their clinical teams was used.

Despite the inclusion criterion of being to speak fluent English, one of the participants brought a friend along to help translate for her. This was not known to the researcher before focus group, and it was felt that the woman should stay and participate as she had made the journey and commitment to attend. The presence of this partial translation during the group did not appear to have any impact on the other women or the findings, as this participant appeared to share many views and themes with the fluent English-speaking women and conversation flowed in this group.

Although the Likert scale was used to characterise overall satisfaction, its use probably did not add anything from the qualitative analysis of the narrative of the focus groups and with such small numbers for quantitative data could not

add anything meaningful, although it did not detract from or contradict the qualitative findings.

Although impossible to prove, another limitation is that it is conceivable that those who did not respond/agree to participate were those who had more negative experiences, both in terms of their breast cancer treatment or the interaction with the medical team. However, this research yielded a response rate of 66% and there were no negative comments communicated from those who did reply but did not attend a group.

In this self-selected group of respondents, it was apparent from discussions that no women had apparently experienced some of the major complications detailed in the scoping review and if any participant had experienced this, it may well have changed not only the discussion but also the tone of that whole focus group. It would have added to the study to have attempted to purposively include women with such experience, but this was not feasible within the population available, all of whom were offered participation and none of whom agreed had this experience. The women who did not participate may have had a different experience and those who did participate are self-selected which is always the case with this type of non-systematic study.

In order to reduce any potential bias associated with self-selection, a case note review was attempted, however as there was incomplete data (only nine of the 14 participants notes were available) and this would be purely from a secondary care setting, with no access to primary care records, this was not considered helpful to present incomplete data and this was abandoned. The essence of this study was to focus on the women's stories and incorporating additional medical data would have made for a different study.

Despite the use of an experienced nurse researcher as focus group facilitator, much of the content and data yielded from the groups pertained to the participants breast cancer experience as a whole. It appeared that they could not disentangle their perceptions of the effect if any that radiotherapy

had on their breast reconstructions. Although all the domains that were discussed within the focus group were mentioned in how they related to this combination of treatment, many of the comments were of a more general nature. It was thought that the fluidity of the group was important and that the facilitator did continually reframe the subject under discussion to this focus. In addition to this the researcher summarised the thoughts of the women at the end of each focus group in order to sense-check and provide an additional opportunity for the participants to detail any specifics that related to post-operative radiotherapy and the effects of.

6.15 Implications of the research findings for clinical practice

The aim of this research was to gain a detailed knowledge of the effects of radiotherapy on TRAM/DIEP breast reconstruction from the patient's perspective. No matter what clinicians may consider the effects of these treatments, the focus should be what the patient experiences and feels the impact is, and the consequences of this combination of treatment. They are the ones undergoing this event and the ones left with any implications and consequences. This being the case, these findings must be disseminated and clinical practice adjusted accordingly.

6.15.1 Summary of findings

The findings illustrated that despite some problems, these women appeared to be fully supported in both their decision-making and experiences of the treatment. They would all recommend this treatment to others who find themselves in the same situation. Healthcare professionals should be informed that, apart from a few comments that related to a lack of information surrounding the bandages used in the immediate post-operative period, information and detail given is satisfactory, as is the information regarding additional avenues for support.

In addition, there is now evidence to disseminate to women that most find this combination of treatment a good option, despite temporary and relatively minor issues that were experienced in the first year.

6.15.2 Implications of findings for healthcare professionals

Nurses and other healthcare professionals must engage the patient in decisions in relation to and regarding their treatment. This research also highlighted once more the importance of good communication with explanations of treatment being key to the patient experience.

The participants did not mention that additional time from the healthcare professionals was required either for them or their family and friends. Many of the participants discussed how their relationships were affected by this treatment and the data was not illustrative of any resulting breakdowns within these associations. Thus, additional support regarding this seems not to be required at the site where this study was conducted.

6.15.3 Dissemination of results – national and international

The intention of this research was to add to the knowledge base of this subject, with the aim of increasing awareness through the evidence of the experiences of this group of women, thus ultimately to improve choice offered and care received by this cohort. This study has produced a wealth of rich data, definite themes and much discussion of experience that will impact the patients themselves, in addition to healthcare professionals. Therefore, it is planned that these key stakeholders should be aware of this research. The results of this study will be disseminated through papers in a range of peer-reviewed journals and presented at local and international conferences.

Since this research has taken place, the researcher has had the opportunity of being part of the London Cancer Alliance working party that were tasked with drafting a policy guidance document associated with immediate breast reconstruction and adjuvant radiotherapy. This has allowed some of the experience and insight gained during the research to be shared with others and the results to a wide audience of local clinicians. Much data that was reviewed for this policy was quantitative in nature and the Schaverian *et al.* (2013) analysis was heavily lent on. The researcher felt a useful part of this

working party and could detail some aspects of the patient's perspective of this combination of treatment.

6.15.4 Dissemination of results - local

The researcher has been asked to take part in a meeting hosted at a local Foundation Trust hospital and invited to share the results and implications of this study.

The Trust where the researcher works hosts monthly 'breast breakfast' meetings where all members of the breast team are invited to hear lectures appropriate and relevant to the field. The consultant oncologist who organises speakers for these meetings has approached the researcher in order a session is taken in order to disseminate these findings.

The researcher is also a member of the Trust cancer CNS group who meet once a month and envisages sharing salient points from this research to this group. The Trust also hosts an annual nursing conference where work is shared and posters displayed. This would provide additional opportunity to share this work to the wider arena.
The researcher would also expect to provide teaching sessions to the breast CNS team that she works within, in addition to the nurses who work on the breast surgical ward and those who work within the radiotherapy[y department.

The researcher Co-chairs the London Cancer Alliance breast nursing group and it is hoped and expected that she will present some of the findings of this study at one of these meetings. Breast CNS from the surrounding 14 Trusts attend these meetings, thus it is hoped some benchmarking of information may take place as a result of this.

The Trust patient information leaflet that relates to this combination of treatment will be reviewed and revised and there is the potential of this leaflet to be adapted and adopted by the surrounding hospitals and used for all

hospitals within the London Cancer Alliance. This is in order that the findings of the research are disseminated to the patients who are given this option of treatment and it is hoped this will assist them with their decision-making. This information may be shared with their families and carers, thus disseminating this information further still.

The researcher will make appointments with the surgical pre-assessment nurses at the Trust in addition to the plastic surgery CNS so that any unmet need regarding the immediate post-operative period be addressed.

6.15.5 Copies of this research thesis and a summary of the research

Participants were asked whether they would like a copy of the papers published from this study. A list of names and postal addresses was collected and papers produced from the research will be sent to all those who request it.

The Breast Cancer Research Trust, who awarded a research grant, will also be provided with a summary paper in which these findings will be illustrated. Charities such as Breast Cancer Care, Against Breast Cancer (who I am a Trustee for) and Breast Cancer Now will also be sent a report summary so this work and the results reach more women.

It is hoped that these opportunities provide the platform and enable the findings of this research to be circulated more widely.

6.16 Researcher's reflection and personal implications for practice

Despite the incredible sensitivity of the subject of this research, the participants appeared positive and uplifting in their comments surrounding their experiences, which is different from the literature. No major psychological or sexual issues were noted; there did not seem to be a huge sense of body-image trauma reported.

What I found surprising was the resilience these women showed despite having undergone such intense treatment, in addition to the unwelcome feelings that accompanied cancer charity advertisements.

Some statements stand out for me, for example one that prevented a participant from attending the cancer support centre while she was in hospital:

'… If women come here to find out and I turn up bald, covered in tubes in a hospital gown, they're going to run for the hills …' (F1:P6:L344)

Others were when one participant referred to the surgery as *'A genius like operation'* (F3:P14:L699) and when one participant stated she looked *'more like a dartboard'* (F2:P7:L550), and how she discussed sharing her body in an intimate situation, wanting to inform her partner rather than pretend *'nothing is lurking underneath'* (F2:P7:L793).

Another powerful comment was from one participant who likened her abdominal scar to having been *'cut in half'* (F2:P9:L174), and alluded to feeling as if she had been *'in the magic show'* (F2:P7:L590).

Although I am not sure as yet exactly how, this research has changed me both as a person and a healthcare professional, and I hope very much that the privileged access I had to these women translates to being able to deliver better care. I feel unbelievably honoured and quite humbled to have been privy to these discussions.

6.17 Areas of further research

This study was limited with regard to both financial and personnel resource. It has, however, produced many findings that can be explored further. One suggestion would be for a large-scale qualitative study that could encompass different geographical areas of the country, as this might shed more light on

the women's experiences, and illustrate whether there are any differences between individual units and the healthcare teams who work within them.

Another area of further research could be to undertake the same size studies at different geographical locations throughout the United Kingdom and compare any aberrations of findings. A large quantitative study could also be performed to add different detail to this subject.

Another possible study could be to investigate the experiences of women who received their radiotherapy prior to their immediate TRAM/DIEP flap breast reconstructions, as this is another combination of treatment offered to this cohort of women. A comparison could be made to identify if there is one order of treatment that women prefer. This study could also be repeated with women who have had implant only breast reconstructions, or for those who had a mastectomy with no reconstruction.

This research could also be repeated with non-English-speaking women in order to identify any marked differences between these groups of women and for women in longer-term follow-up.

6.18 Summary of chapter

This chapter has provided discussion of the research findings against the backdrop of literature. It yields evidence to suggest that the combination of post-operative radiotherapy on immediate TRAM/DIEP flap breast reconstructions is acceptable to the patients undergoing this treatment. The breast cancer experience these participants encountered was discussed, along with three meta-syntheses that reviewed qualitative work within this arena. The themes of my findings provided structure for this discussion and comparisons, and differences or omissions of previous reviews were detailed. Strengths and limitations of the study were illustrated along with areas for further research and implications for clinical practice.

Chapter 7: Conclusion

7.1 In summary

There are a number of different options regarding breast reconstructive techniques, and literature about the timing of these in the context of delivering radiotherapy is controversial. There is an absence of randomised controlled trials, and evidence is both conflicting and confusing. Moreover, due to the nature of the cohort of women who require this combination of treatment, sample size within these studies is small. The use of physical examination, photographs and volume measurement as outcome measures is inconsistent and studies, in the main, concentrate on quantitative data made up of clinician and/or patient points of view. Furthermore, there is contradictory grouping within these studies, as many group different reconstructive techniques together, reporting on them as a whole. The indications of fat necrosis, flap contracture or a worsening cosmetic outcome are discussed within this arena along with comorbidities such as obesity, increasing age and smoking. There is no uniformity in reference to re-operation rates, as a number of studies pool secondary cosmetic operations, such as nipple reconstructions, within the same group as re-operations required due to post-operative complications.

Notwithstanding what is illustrative of the research to date is that this issue remains controversial and so the debate continues. Despite this lack of data, there appears to be a general unease amongst clinicians about offering this combination of treatment, which may result in some women potentially not being offered this choice of oncological management.

My study concentrates on qualitative data from the patients who have received radiotherapy post immediate autologous breast reconstruction within the London teaching hospital where I work, and reports there were no major issues experienced by this cadre of women. Thus, the potential use or requirement of radiotherapy in this setting should not deter this combination of treatment from being offered.

7.2 In conclusion

Breast cancer is a potentially life-threatening disease and, once the initial treatment is completed, side effects may continue. After treatment the patient may look different physically and feel different emotionally. This research adds to the knowledge base that surrounds the topic of immediate TRAM/DIEP flap breast reconstructions in combination with post-operative radiotherapy as it highlights the women who have undergone this do not consider it to be problematic or an identifiable issue of concern. It is hoped that this will furnish the medical community with increased information from the patients themselves whose views are crucial in this situation that the focus should be patient-centred care: fitting the organisation, services and treatments offered around the patient, as opposed to fitting the patient around the organisation, its services and treatments.

Within the six themes, statements referred to what the women experienced at the time of the treatment and also presented thoughts and feelings regarding their encounter. Comments related to how they felt psychologically and physically, in addition to what had happened within their social environment as a result of their breast cancer treatment. Many comments concentrated on their experience at the time and immediate effects of treatment received; the operation and initial radiotherapy side effects rather than the lasting, long-term effects still being experienced. Equally, support received at the time (from healthcare professionals, family and friends) was contemplated and discussed at length; there were fewer comments related to how this support now impacts their lives or how life has changed. Many chose to contribute historical accounts from their treatment as opposed to the 'here and now' which might have tied into the research question a little more. Notwithstanding, minimal concerns remained in relation to the question of the impact of radiotherapy on these immediate autologous tissue breast reconstructions in this sample of women.

The project started with the researcher feeling protective and slightly anxious that women who have radiotherapy post immediate TRAM/DIEP flap breast reconstruction may either be left with complicated consequences of this combination of treatment, or not appreciate how immense this treatment and its effects are; infringing on possible issues regarding informed consent. This study has shown the researcher that information appears to be pitched at the correct level, which the participants felt this combination of treatment is well tolerated with minimal side effects and is one that these participants would recommend to others in a similar situation.

7.3 The future

There are a plethora of clinical trials that are being conducted within the arena of breast cancer and many are associated with the delivery of radiotherapy, streamlining this treatment and the dose required in order to gain oncological benefit. This, along with increased access to these reconstructive techniques may mean that the future will see a sea change and that there are potentially more autologous flaps that are irradiated. As always, treatment plans should be discussed through multi-disciplinary meetings and a robust pathway should be decided upon. This study adds to the evidence-base, giving additional insight into what women experience and feel regarding this subject, and should be used as part of the decision matrix at these meetings. The specialist nurse should be armed with this evidence and act fully as an advocate and in the best interest of the patient when these treatment discussions occur.

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Appendices

Appendix 1: Chart of radiotherapy effects on TRAM/DIEP reconstructions studies (red papers)

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Albino *et al.* (2010) USA	To assess the impact of DXT on autologous breast recon To identify pt and treatment factors affecting recon outcomes	N=76 Retrospective study Single centre Analysis of medical records over a 9 year period	Co-morbidities, complete and partial flap loss, fat necrosis, fibrosis, retraction, further surgery, excessive pain, hyperpigmentation	Complications in 53 pts (70%) 36 pts (47%) required further surgery.19.7% developed fat necrosis and fibrosis 30.3% tissue retraction, 2-fold increase in skin complication rates and 5-fold increase in total complication rates for pts who smoke, have diabetes or have neoadjuvant chemotherapy	DXT post recon can be successful but pts with specific risks (diabetes, smokers, pre-operative chemotherapy) should be aware of complications.

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Carlson *et al.* (2008) USA	To examine the effect of DXT on pedicled TRAM recons	N=199 5 groups – TRAM and DXT = 25 Retrospective study Single centre Median f/u = 26.4 mths Data obtained from personal communication, physical examination, chart and photographic review, 4 judges who were blinded to the study reviewed charts Variance tests	Volume of breast mound, contour of breast mound, placement of breast mound, inframammary fold, Additional surgery, Cosmetic score, Flap complications	Flap complications rate – 34.2% recon no DXT – 60% in DXT pre TRAM – 44% in DXT post TRAM Immediate TRAM and no DXT group had best cosmetic outcome, No statistically significance in fat necrosis occurrence for TRAM flaps who had DXT (trend towards an increase)	DXT has effect on cosmetic outcome of pedicled TRAM whether before or after recon. Better to delay recon if having DXT.

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Chatterjee *et al.* (2009) UK	To measure whether DXT on DIEP recons affect volume	N=68 N=46 – recon no DXT N=22 – recon and DXT Prospective study Single centre Volumetric assessment carried out a minimum of 1yr after surgery, Used mammometer, Assessed the intra-operative flap data in grams on flap recons to allow for analysis of volume change over time with or without DXT	Volume change of DIEP flap	No statistically significant difference in volume change between pts who did or did not receive post op DXT	DXT should not deter women from immediate DIEP recons

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Foster *et al.* (2005) USA	To examine if immediate TRAM recon and post-op DXT is safe and effective	N=252 N=35 required DXT Retrospective study Single centre Mean f/u = 48 mths Case series of consecutive pts Chart review to decipher complications	Flap loss, fat necrosis, flap volume loss, adjuvant treatment delay, need for additional surgery	100% flap survival 3 pts (9%) had flap necrosis, 2 pts (6%) had additional surgery due to volume loss, no delay in pt treatment, 2 pts (6%) had cellulitis	TRAM recon followed by DXT is safe, with minimal morbidity and no significant change in tissue volume.
Halyard *et al.* (2004) USA	To determine the effects of post-op DXT on TRAM flap viability and cosmesis	N=15 Retrospective study Single centre Review of charts between given time Medical notes studied 14/15 pts asked to rate their cosmesis excellent to poor median f/u=26.4 mths	Surgical complications, acute and chronic side effects of DXT and cosmetic outcome	9pt (60%) developed mild erythema 2pts (13%) moderate erythema 1pt (7%) severe erythema 6pt (40%) dry desquamation 2pts (13%) had fat necrosis post DXT 14pts (93%) retained flaps 13pt (87%) rated cosmetic results good to excellent	TRAM flaps can be irradiated with few complications and acceptable cosmetic results

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Hanks *et al.* (2000) USA	To analyse acute effects of post-op DXT on TRAM recons	N=25 Retrospective Review all pt notes between 1985–1999 Single centre	Degree and incidence of erythema, desquamation and need for treatment breaks	12 pts (48%) developed mild erythema 13 pts (52%) developed moderate or brisk erythema 10 pts developed desquamation	DXT on TRAM recons is well tolerated and has no increase in side effects Smokers do not have increased rates of erythema or desquamation, prior chemotherapy, radiotherapy and the presence of fat necrosis are also not factors for increased skin reaction

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Huang *et al.* (2006) China	If there is an effect of DXT on TRAM recon (To compare local recurrence and distant metastasis in pts who had DXT post TRAM recon)	N=191 N=109 – non TRAM N=82 – TRAM and DXT Retrospective study Single centre Records reviewed Acute and late effects on flap recon recorded Asked pts in clinic or on telephone (N=23)	Skin reaction evaluated according to Radiation Therapy Oncology Group score, Pts evaluation regarding to contracture, volume loss and cosmetic result	All pts developed some degree of hyperpigmentation and skin erythemia 36% (21pts) experienced contracture, 36% (21pts) partial volume loss, 8.5% (7 out of 82) increase of fat necrosis for those post DXT 70% rated cosmetic score excellent and good No statistical significance in acute skin reaction, No flap loss	Acute and long-term effects of DXT on TRAM was well tolerated and manageable, (Immediate recon did not increase locoregional recurrence or distant metastasis)
Hunt *et al.* (1997) USA	To evaluate post-op DXT after TRAM recon	N=19 Retrospective Single centre Charts reviewed Pts examined in clinic and interviewed on the telephone	Flap viability Cosmetic results Locoregional recurrence	No TRAM flap losses 2 pts developed fat necrosis 84% of pts rated cosmesis excellent/good 1 pt rated a poor cosmetic result Free TRAM had more volume loss than pedicled TRAM	Post-op DXT can be given to TRAM recon with excellent cosmetic results

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Makmur *et al.* (2003) Singapore	To see if the fat necrosis rate in DIEP recons increased with DXT	N=33 Retrospective study Single centre DXT post recon N=11 Observed the sample	Incidence of fat necrosis	2 pts had fat necrosis before DXT, this did not change 2 pts had mild desquamation and skin hyperpigmentation 6 mths post DXT	Fat necrosis rate did not change regardless of DXT Age of the pt was the risk factor – pts over 50 yrs had more complications
Mehta & Goffinet (2004) USA	Does post-op DXT effect TRAM recon	N=22 Prospective study Single centre Median f/u=18 mth Report of experiences Physician and pt reports on cosmesis	Acute side effects Flap viability Cosmetic outcome	66% received treatment with no breaks, all pts developed some degree of mild erythema and skin tanning during treatment 10% desquamation 30% grade II erythema no flap loss, physician and pt reported cosmetic results was good	DXT on TRAM recons is not associated with an increase in acute complications.

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Moscona *et al.* (2006) Israel	To identify patient satisfaction & aesthetic results after pedicled TRAM recons	N=101 Retrospective study Single centre Review of medical notes and pt questionnaire Av age – 49 65% immediate recons 35% delayed recons N=48 nipple recons. Some had DXT ?number, ?pre- or post-operatively	General satisfaction, aesthetic aspects, effect on relationship with spouse, symmetry, satisfaction with scars, satisfaction clothed, sensation	75% satisfaction re surgical outcome, 55% absolute satisfaction, 86% satisfied when dressed, 48% satisfied when nude, 40% satisfied with sensation of breast, 82% satisfaction by spouse, 90% state no change in sexual attractiveness, Larger breasted women were less satisfied in clothes Better educated women had more drastic changes in body image perception, Better educated women had a lower satisfaction from spouse, Women who had DXT had lower satisfaction scores, esp with sensation	POOLED DATA– no idea of number who had DXT and if this was pre- or post-operative. Younger women were more satisfied with results Women post DXT (?pre or post-op?) were less satisfied Women post delayed recons were less satisfied

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Proulx *et al*. (2002) USA	To identify if there is a negative impact after DXT of TRAM flap	N=36 N=15 recon and DXT N=8 recon N=7 delayed recon Retrospective study Single centre Median f/u=36 mths Review medical notes, physical exam, questions to pts	Cosmetic results judged by plastic surgeon and pt for shape, size, skin texture and colour	14/15 judged to have excellent cosmetic outcome 1/15 reported dissatisfaction as they had flap loss	Excellent cosmetic results can be achieved and viability of TRAM is not affected by DXT
Rogers & Allen (2002) USA	To establish an association between DXT and poor post-op results in DIEP flaps	N=60 Retrospective study Single centre 30 irradiated pts paired with non-irradiated pairs (matched for age and BMI) for complications. Aesthetic evaluation to compare 10 pts before DXT and 10 pts at similar time from non DXT arm	Incidence of fat necrosis, fibrosis/shrinkage, flap contracture. 5-point scale to evaluate symmetry, aesthetic proportion, appearance of superior pole of breast	Statistical significance in cosmetic scores for DXT arm. Incidence of fat necrosis, fibrosis and flap contracture higher in DXT arm. 23% incidence of fat necrosis 5 pts required surgical review	DIEP recon should be delayed until after DXT. Pts who smoke or are obese are at particular risk for complications

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Sitathanee *et al.* (2005) Thailand	To study the acute effects of DXT after TRAM recon	N=10 Retrospective study Single centre Medical notes reviewed Pts reviewed weekly during DXT and at 1 and 2 mths post completion	Acute effects or toxicities of DXT	3 pts = erythema or mild hyperpigmentation, 4 pts = moderate hyperpigmentation, 3 pts = skin desquamation	DXT post TRAM is well tolerated and not associated with an increase in complications
Spear *et al.* (2005) USA	Examine effect of post recon DXT on TRAM recon	N=171 Retrospective study Single centre 3 groups compared Pre TRAM DXT = 42 Post TRAM DXT = 38 TRAM no DXT = 91 Clinical photos reviewed by blinded reviewers (n=16) Non parametric tests	Overall cosmetic outcome, symmetry, flap contracture, hyperpigmentation	No statistical significance between the groups in flap complication, Control group rated best regarding overall cosmesis, symmetry and contracture. Control group had statistically significantly less hyperpigmentation, Pre-op DXT rated next for cosmesis, symmetry and contracture	TRAM recon recommended to be postponed in pts known/expected to receive DXT. First study to critically evaluate cosmetic effects

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Tran *et al*. (2000) USA	To evaluate the effect of post-op DXT on TRAM recon	N=41 Retrospective Single centre Average f/u=3 yrs – all at least 1 yr post DXT Data collected through personal communication, physical exam, charts, photographic review, comparison with contralateral breast	Flaps evaluated for volume loss, hyperpigmentation, palpable fat necrosis, firmness, skin contracture (Baker III and IV), loss of symmetry	No flap loss occurred, 10 pts (24%) demonstrated severe contracture and required secondary flap surgery. 14 (34%) had palpable fat necrosis 56% noted a firm recon 78% had loss of symmetry 37% had hyperpigmentation	Post-op DXT found flaps fared statistically worse for hyperpigmentation, fat necrosis, firmness, flap contracture when compared to non-irradiated flaps
Tran *et al*. (2001) USA	To compare the outcome of immediate and delayed free TRAM flap recons in pts who received post-op DXT	N=32 DXT after TRAM N=70 DXT before TRAM Retrospective study Single centre Review of personal communication Pt charts	Compare early and late complications. Early-vessel thrombosis, flap loss, skin flap necrosis, wound healing problems Late-(1 yr post DXT) Fat necrosis, flap contracture (Baker III and IV)	Rates of fat necrosis, flap volume loss, flap contracture were significantly (p=0.000) higher in recons that had DXT rather than those recons post DXT 24/32 pts had contracture 9 pts (28%) needed further flap surgery or an external prosthesis	Recon should be delayed for those needing DXT after free TRAM. Early surgical complications did not vary between gps. Incidence of late complications was higher in pts who had DXT after TRAM

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Watterson *et al.* (1995) Australia	Describe pertinent anatomy and define significant risk factors to aid pt and flap selection for TRAM recons	N=556 (n=198 immediate) (n=531 delayed) Retrospective study Single centre Venous injections to map venous architecture 31.6 mths mean interval post op Explore smoking levels and complications Records of pts reviewed	Partial flap loss Fat necrosis Estimation of volume and flap loss Abdominal wall hernia Wound infection Haematoma Other complication	23.7% overall complication rate Risk factors associated included smoking, chest wall DXT, obesity and significant abdominal scar. Diabetes, age and hypertension were not risk factors. 59 pts (10.6%) developed fat necrosis, of these 28 (5%) had partial flap loss. No total flap loss. DXT, abdominal scar and obesity was significantly associated with increased fat necrosis. DXT and hypertension were risk factors for partial flap loss.	Pt selection is a fundamental determinant of successful TRAM flap recon DXT and TRAM recons have more fat necrosis and flap loss – although it is UNCLEAR IF DXT PRE OR POST OP

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Williams *et al.* (1997) USA	The presence and nature of DXT changes to pedicled TRAM recon	N=699 TRAM then DXT =19 DXT then TRAM = 108 TRAM only = 572 Retrospective study Single centre Review of pt charts Mean f/u = 47.6 mths	Complications – fat necrosis, fibrosis, full-thickness skin loss, breast infections, seromas	10 pts 52.6% demonstrated post DXT changes 6 pts (31.6%) required additional surgery Overall complication rates were higher but not statistically significant. Fibrosis seen in 31.6% of post op DXT on TRAM, with 2 requiring extra surgery	Complication rates do not change if DXT given pre or post TRAM, but their nature does (fat necrosis to fibrosis) TRAM then DXT has significantly more fibrosis than for those with no DXT.
Zimmerman *et al.* (1998) USA	To determine the effects of post-op DXT on flap and local control outcomes for immediate free-flap TRAM recon	N=21 Retrospective study 2 centre study Patient interview Average f/u =19 mths (1–62 mths)	Flap complications, overall cosmesis, Local recurrence rate	No flap complications or losses, Cosmesis reported as excellent – 60% (n=12) Good – 30% (n=6) Fair –10% (n=2) 3 thought DXT had improved cosmesis 1 thought worse, 16 pts thought no effect 86% local control rate	DXT on TRAM flap recons appear safe and cosmetically acceptable

Appendix 2: Chart of radiotherapy effects on TRAM/DIEP and implant reconstruction studies (black papers)

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Adesiyun *et al.* (2011) USA	To identify how the sequencing of post mastectomy DXT and breast recon affects time to development of complications or patient satisfaction with breast recon	Retrospective study Single centre Review of medical notes Pts posted a questionnaire N=113 N=57 DXT then recon N=69 TRAM/DIEP N=30 LD N=14 implant N=1 implant & TRAM N=23 TRAM then DXT N=13 implant then DXT N=14 LD then DXT 1 site	Capsular contracture Implant problems Partial flap loss Haematoma Infection Seroma Wound problems Fat necrosis Pt questionnaire	32% overall complication rate for pre-op DXT 44% rate for post-op DXT Higher acute complications & late complications for recon first Most common complications after tissue-only recon was fat necrosis, flap loss TRAM plus post-op DXT – 9% (2/23) early complications – 29% (6/23) late complications General satisfaction & aesthetic satisfaction comparable Analysis by recon type similar	Numbers of recons & respondents do not add up ?some bilateral Sequencing of DXT & recon did not have substantial impact on risk of complications or on pts general or aesthetic satisfaction. Recon then DXT had more late complications Too few pts in each group to have statistical power for each recon

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
Alderman *et al.* (2002) USA	To describe and compare complication rates with 3 recon techniques. To evaluate procedure timing, smoking status, BMI, age, chemo and DXT.	Prospective study 12 centre study N=326 Pedicle TRAM n=96 Free TRAM n=48 2 years after surgery complication data was collected from pt records and telephone interviews	Total complications and major complications OAB, wound healing probs, re-operation, hospitalisation	52% complication rate with immediate TRAM recons vs 32% for delayed TRAM Free TRAM had more complications than pedicled (46% and 31%) – not significant BMI was positively associated with complications, smoking, DXT, chemo did not have significant effects	Immediate recon's and obesity have significantly more complications than delayed recons. Recon type has no significant effect on complication rate. Age, chemo and DXT do not affect complication rate, but there is a trend for TRAM and chemo Post-op DXT variable is grouped with all recons – can't decipher which is DXT and TRAM
Anderson *et al.* (2004) USA	To report complication rates and	N=85 Retrospective study Single centre	Actuarial incidence of complications	3-year actuarial complication rate was 21% – no difference between 2 recon types	No complications post DXT on TRAM recon

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
	cosmetic outcomes among pts post recon and DXT	TRAM =35 Implant=50 Recon and DXT = 70 DXT pre recon = 15 Multidisciplinary review of charts Mean f/u = 28 mths Cosmesis analysed from chart review at f/u	involving the recon Cosmesis	No major complications in TRAM group 2 major complications rates in implant group Significantly higher minor complications in TRAM group (27% vs 14%) (fat necrosis, fibrosis) Cosmesis of TRAM group significantly better than implant group	And superior cosmetic scores to implant recons after DXT
Berry *et al.* (2010) USA	To evaluate risk factors for breast recons & determine if DXT increases complication rates	Retrospective study Single study Review of medical database noting age, BMI, smoking, hypertension, diabetes, chemo, DXT (pre and post op) Review of tissue-only recons compared to implant N=733 implant N=425 tissue-only	Minor complication rates (haematoma, wound problems, flap necrosis, implant problems) Major complications rates (re-operations)	No statistically signif difference between DXT and no DXT with TRAM recons BMI>30 had more complications Tissue-only complication rates – N= 116 smokers N=114 hypertension N=20 diabetic N=183 (40%) post-op DXT N=108 (24%) pre op DXT N=139 (32%) BMI>30 75% immediate recons Total complication rate – 32% Minor – 30% Major – 20% BMI over 30 signif increase in	BMI over 30 signif increase in minor and major complications (No impact of age, smoking, hypertension) BMI over 30 converted to 4.1fold increase of major complications for tissue-only recon No impact of DXT on tissue-only

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
				minor and major complications Age, smoking, hypertension did not impact	UNSURE of numbers of post-op DXT & TRAM (states those who were known to need post op DXT had implant recon & delayed tissue-only recon) POOLED DATA for tissue-only (TRAM, DIEP & LD)
Chawla *et al*. (2002) USA	To measure complication rate and cosmesis for pts with TRAM and implant recon and DXT either before or after recon	N=48 Retrospective study Single centre TRAM n=30 TRAM with post-op DXT n = 16 (implant recon n=18) Mean f/u 32 months Retrospective multidisciplinary review of charts Cosmesis analysed by chart review using	Quality of recon post DXT and complications of wound healing, infection requiring ABs, signif fibrosis, fat necrosis, implant failure, chronic pain, contracture Cosmetic outcome	Complication rate was 12% for TRAM and 53% for implant recon Cosmetic outcome was significantly better in TRAM recons (90% good/excellent cosmetic result for those having DXT post TRAM recon	TRAM recons either before or after DXT had satisfactory cosmetic outcomes and complication rates TRAM have fewer complications and better cosmesis

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
		physician comments and pt complaints			Pre and post-op DXT on TRAM recons does not affect complication rate Co-morbidities of smoking, diabetes and peripheral vascular disease have no effect on complication rate
Christante *et al.* (2010) USA	To identify factors independently associated with surgical complications & recons (& sentinel node biopsy) to predict post-op DXT	Retrospective study Single centre Review of institutional cancer registry N=152 recons N=131 immediate ?numbers of types of diff recons	Complication rates requiring re-operation	DXT affects implant recons ?tissue-only	Pooled data No idea about DXT and tissue-only recons **Not relevant for review**
Jhaveri *et al.* (2008) USA	To determine long-term complication rates and	N=92 Retrospective study Single centre TRAM=18	Functional complications and cosmesis compared for pts	33% of implant recons had poor functional results 0% of tissue recons 51% of pts with implant recons	TRAM and DIEP recon is associated with fewer long-term

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
	cosmetic results for pts undergoing post-recon DXT	DIEP=3 LD=2 Implant=69 All had DXT Median f/u 38 months Reviewed pt records Telephone interviews with pts to gauge functional outcome and cosmetic results	with implant and non-implant recons	reported satisfactory cosmesis compared to 83% of those with tissue recon	complications and better cosmetic results after DXT
Kuske *et al.* (1991) USA	To evaluate cosmesis, complications, pt satisfaction, and tumour control in pts receiving DXT and breast recon	N=72 Retrospective study Single centre N=66 recon and DXT- pre or post op N=43 (60%) immediate recon N=23 (32%) delayed recon TRAM =9 N=44 who had DXT post recon Review pt charts Median f/u = 4 yrs Cosmesis evaluated photographically by a panel of physicians,	Tumour control. Complications, cosmesis, pigmentation, symmetry, pt satisfaction	TRAM had best cosmetic scores 48% of pts would choose to have the same recon procedure again, 56% (n=5) of those with tissue-only recons had complications, Physicians less likely to judge cosmesis 'excellent' than pts, (cosmetic failure 51% physicians, 33% pts), cosmesis better in younger pts than in older ones, 58% judged by physicians to have normal pigmentation, 17% moderate hyperpigmentation, 17% slight	DXT and breast recon are compatible, but timing and techniques should be considered. Unclear if dxt given pre or post op – pooled data **Not relevant for review**

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
		Pts asked if they would repeat experience or not, Tonometry measurements used			
Lee *et al*. (2010) USA	To examine the complications and pt satisfaction for those who have recon in relation to whether DXT was given before or after recon compared with a control group who had recon and no DXT	N=919 Retrospective study Single centre DXT before recon=57 DXT after recon=59 No DXT=665 (Autologous then DXT=36) Review of case notes Validated questionnaire assessed pt satisfaction (response rate=73.7%)	Complication rates that required additional surgery Pt satisfaction survey	Overall complication rates for DXT before and after recon were higher than the control. Recon then DXT had increased complication rate compared to controls, but cosmetic outcome was similar. DXT before recon had lower complications than DXT after recon – not statistically significant though. DXT before recon has similar complication rate to control, but worse cosmetic outcome. Pts with autologous recons had comparable rate of fat necrosis to control group, but 2 pts required further flap surgery. Higher rate of satisfaction with autologous recons.	DXT after all recons causes more complications, but cosmesis is the same as for those who do not receive DXT Pts with autologous recons had comparable rate of fat necrosis to control group, but 2 pts required further flap surgery
Losken *et al*. (2004)	To determine the number of	N=888 Retrospective study	Number of secondary	Pts with any complication had higher rates of secondary	DXT significantly impacted the

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
USA	secondary procedures to complete breast recon and factors that influence this process	Single centre TRAM=643 Other recon = 245 Immediate recon= 381 Delayed recon=499 Mean f/u 28.5 mths Number of secondary procedures noted along with other variables – delayed	operations to complete recon until nipple recon	procedures Delayed recons and TRAM recons had higher number of procedures DXT increases number of procedures	need for secondary procedures Pooled date – cannot decipher which type of recon had DXT
Mosahebi *et al*. (2007) UK	To compare cosmetic outcomes of 3 types of recons and the effect of DXT	N=60 Retrospective study Single centre DIEP=10 (17%) Implant and LD with implant = 50 (83%) Post-op DXT=20 (28%) Mean f/u = 48 months Evaluation methods were tonometry, clinical evaluation, photography-based assessment and pt satisfaction survey	Cosmetic outcome	Tonometry index for DIEP recons were significantly higher than other recons No difference in clinical evaluation scores with any of the recon types or after DXT No difference in photographic evaluations for recon types Pts were satisfied with all types of recon	Similar cosmetic outcomes are achieved with all types of recon. DIEP recons achieve a better cosmetic outcome after DXT compared to the other types of recon (with implants)
Roje *et al.*	To identify	2 centre study	Results of 3	Statistically signif more	Age and smoking

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
(2010) Croatia & Austria	significant risk factors, assess aesthetic outcome & patient satisfaction with breast recons	Retrospective study Review of consecutive cases N=101 N=75 tissue-only N=16 LD N=10 implant N=48 pre op DXT N=9 post op DXT N=45 pre op chemo F/U 6 mths post op 3 types of questionnaire *personal/medical *aesthetic assessment *psychosocial assessment	questionnaires Complications – flap necrosis, implant problems, hernia, infection, DVT, PE	complications (infection, heart failure) in obese pts, No relationship between age or smoking and complications, In DIEP complications signif higher with post-op DXT, No signif results in aesthetic outcome or pt satisfaction and recons.	do not have effect on complications rate, BMI and DXT do have effect, No aesthetic or pt satisfaction differences. No's in sample do not add up. Pooled data re diff recons and if received DXT. Only 9 had post op DXT on ?which recon
Rusby *et al.* (2010) UK	To compare autologous with implant recons in terms of re-operation rates, recon failure and impact of DXT	N=110 Prospective study Single centre DIEP=37 No DXT=69 N=11 – pre-op DXT (all recons) N=26 – post-op DXT	Re-operation rate within the 5-year f/u period	Re-operation rates higher in implant recons, although not statistically significant	No difference in re-operation rates for those who had and did not have DXT, although pattern of loss of implant recon was statistically

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
		(all recons) Medical notes examined			different according to exposure to DXT This study groups the pre and post op DXT.
Shaikh-Naidu *et al.* (2004) USA	To determine differences in satisfaction between TRAM and implant recon	N=211 Retrospective study Single centre TRAM = 105 TRAM and DXT = 6 Implant=160 Patient survey with 5-point Likert scale	Cosmetic satisfaction based on breast shape, size, symmetry, scaring and sensation	TRAM recons were rated higher by pts than pts post implant recons. Presence of nipple-areola complex recon positively influenced majority of parameters. Post-op DXT resulted in lower satisfaction scores	Cosmetic satisfaction is greatly influenced by a nipple-areola recon. Age, timing and DXT also influence although to lesser degrees
Soong *et al.* (2004) China	To evaluate clinical outcome and cosmetic outcome of pts who received DXT post recon	N=25 TRAM=21 (84%) LD=4 (16%) Retrospective study Single centre Review of records Median f/u = 3.7 yrs Radiation side effects were graded using RTOG/EORTIC	5-year actuarial, local failure-free rate, disease=specific survival and progression-free survival Cosmetic satisfaction by pts	Only mild acute skin reactions reported No flap necrosis or flap loss noted No additional surgery required Cosmesis rated as good or excellent in 85% of pts	Post-operative DXT after autologous recon is well tolerated and not associated with increased complications

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
		criteria Cosmetic assessment by pts			
Stralman *et al.* (2008) Denmark	To investigate long-term outcomes for women with immediate breast recons	Retrospective study Single centre Review of medical notes Mean F/U 34 +/-30 mths N=145 N=82 implant N=33 TRAM N=30 LD N=24 had DXT	Late complications – re-operation, implant issues, fat necrosis, other	No link between DXT and capsular contracture Recons with implants have higher re-operation rates	POOLED DATA UNSURE who had DXT of recon groups. No mention of DXT & TRAM More complications with implant recon than tissue-only **Not relevant for review**
Tran *et al*. (2011) USA	To determine differences in surgical outcome associated with post op DXT for breast surgery	Retrospective study Single centre Review of notes of recons from 2005–2010 N=175 80% = mastectomy N=63 tissue-only (those who had DXT = 51) N=21 implant	Proportion of pts having post op complications - overall - infection - fat necrosis - flap necrosis - implant problems - skin loss - lymphoedema	There was no statistically signif difference in complication rate in radiated and not radiated group for those with recons. Significantly higher proportion of lymphoedema in irradiated group	DXT did not impact surgical outcomes, although lymphoedema occurred more commonly post DXT. Independent effects of tissue-only vs implant

Author, Year & Location	Research question	Design/ Methodology	Outcome measures	Results	Conclusion/ comments
		N=12 tissue & implant N=106 delayed recon 25.7% received DXT Median F/U=355 days			recons cannot be determined. Pooled data numbers do not add up complication rate not separated into type of recon
Wong *et al.* (2008) USA	To evaluate the likelihood of requiring further corrective surgery after recon and DXT	N=62 Retrospective study Single centre TRAM=42 Other recon=20 All had DXT Median f/u=13 mths Retrospective study Data on complications and cosmetic outcome were taken from pt records, operation notes and personal communication	Major complications needing corrective surgery (implant removal, surgical intervention of infection, significant scar tissue). Minor complications also (excision of dense fibrosis, fat necrosis, liposuction, capsular contracture release)	26 (41%) pts underwent further corrective surgery 9% of non-implant recons needed further corrective surgery 40% of implant recons underwent further surgery Re minor surgery – 14/48 (29%) non-implant and 2/15 (13%) implant	Implant recons have a higher rate of needing further surgery after DXT If DXT is required post-op, advise tissue recon

Appendix 3: Patient information letter

Trust logo
xxxxxxx
xxxxxx
P: 0203 xxx xxxxx
F: 0203 xxx xxxxx
E: Victoria.harmer@xxxxx
W: www.xxxxxx

Women's Perspectives of Radiotherapy combined with Tissue-only Immediate Breast Reconstructions

PARTICIPANT INFORMATION STATEMENT

FINAL FOCUS GROUP DATE – xxxxxxx

I would like to invite you to take part in a research study taking place at xxx NHS Trust.

Before you decide whether to take part, please read this participant information sheet.

This information sheet tells you about what the study involves and how you can help. Do talk to others about this study if you wish.

What is the study about?

You are invited to take part in a research study into what patients think about the radiotherapy they received and their tissue-only immediate breast reconstruction.

The aim of this study is to investigate what women think and feel about having radiotherapy after tissue-only breast reconstructions. The results will help us develop better information for women in the future who are going through these treatments.

Who is undertaking the study?

The study is being conducted as part of a doctorate in Healthcare/Nursing at Kings College London by Victoria Harmer, xxx in the breast care unit at xxx. The surgeons, plastic surgeons and the oncologists at the Trust are informed and have approved this study. Vickki has also received a small research grant from 'xxx'.

Why have I been invited to take part in this study?

The people eligible to participate in this study are women who have had radiotherapy to the breast area after an immediate breast reconstruction; that is a reconstruction created at the same time as the removal of the breast. The reconstruction also needs to be a tissue-only reconstruction (without the

use of a silicone implant), and the tissue needs to be from the abdomen (tummy). Your treatment would have been between 1–5 years ago. Essentially we want to find out your views and perspectives on radiotherapy and your breast reconstruction.

What does the study involve?
If you agree to participate in this study, you will be asked to take part in a discussion session (focus group) with a small number of women (about 6–8) who have had radiotherapy after this type of reconstruction. The session will be led by an experienced nurse facilitator who will guide the discussion using a series of questions to prompt your responses. During the session, some information will be presented that may be new to you.

You will need to attend a focus group facility at the xxx, xxx Hospital, xx for about two hours on one occasion. On arrival, you will be asked to complete a short demographic information form. This is to help to describe our findings and those who participated in the study.

The focus group discussions will be audio-recorded and typed up. If you take part in a focus group and wish to withdraw after the session has commenced, you are free to do so. This will not affect the compensation you receive for volunteering your time. However, it will not be possible to exclude your individual data after we have started analysing the information.

At the end of the focus group, Vickki will ask if you would like to be contacted by telephone about a week after the group. This is to find out if there have been any further thoughts or feelings since the focus group.

Expenses and Payment
You will receive a £20 voucher for your time and we can reimburse travel expenses, and light refreshments will be provided.

Do I have to take part?
You do not have to take part, your participation is voluntary. If you do not want to take part decide you do not have to give a reason. Please do however fill out the 'Reply Slip' or email Vickki (email address as above) if you do not wish to participate in order you are not contacted about this again.

What are the possible benefits of taking part?
There may be no benefits to you in taking part, however some women find sharing experiences helpful and this may give you the opportunity of doing this.

The focus groups will take place at xxx, a charity-run centre which offers support and guidance to those after a diagnosis of cancer. If you have not been involved in the centre previously, you may find being able to access this support a benefit.

This research may lead to a better understanding of women's thoughts of radiotherapy and their breast reconstruction.

Will my taking part in the study be kept confidential?
All aspects of the study, including results, will be strictly confidential and only the study investigator and her supervisors will have access to the data.

Storage of data, confidentiality and anonymity
Study materials will be stored in a locked filing cabinet located in a secure office and all data will be destroyed after seven years. A report of the study may be presented at a conference or in a scientific publication, but individual participants will not be identifiable in such a report. Electronic transcription (files) will be password protected and you will not be identified by name.

What will happen if I don't want to carry on with the study?
It is up to you to decide to join the study. If you agree to take part, we will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

Whatever your decision, it will not affect your relationship with XXXXor your future care.

What will happen to the findings of the study?
The study findings will be published in nursing journals and used for educational purposes at Kings College London. If you would like to access the findings these will be available by emailing the researcher at the address above.

What do I do next?
When you have read this information, please decide whether you are interested in taking part in this study and please fill out and return the 'Reply Slip' even if you are unable to participate in order Vickki does not bother you further. Please return the 'Reply Slip' in the stamped addressed envelope provided.

If you wish to participate, we will then arrange a time when it is convenient for you to attend the focus group.

If Vickki does not hear from you, in about a week, she will telephone you to ask if you would like to participate. If you would prefer, please reply to Vickki on the numbers or email address at the top of this letter.

The last focus group will be held at xxxx on:

- **2–4pm Thursday October 10th 2013**

If you would like to know more at any stage, please feel free to contact Vickki Harmer on xxx or email Victoria.harmer@xxxxxx

This information sheet is for you to keep.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by NRES Committee West Midlands – Black Country Research Ethics Committee and xxxx.

Reply Slip

Name:
Contact number:
Best time to telephone you:
Email:

I would like to attend (please tick)

- 2–4pm Thursday 10th October 2013 ☐

- I would like to attend but unable to at the above time ☐

- **Sorry I am unable to participate in this research** ☐

Please complete and send back using the stamped addressed envelope or email this information to Vickki via Victoria.harmer@xxxx

Appendix 4: Research Ethics Service approval

NHS
Health Research Authority

National Research Ethics Service

NRES Committee West Midlands - The Black Country

[redacted]

Telephone: [redacted]
Facsimile:

26 July 2013

Miss Victoria Harmer
[redacted]

Dear Miss Harmer

Study title:	**Women's perspectives of radiotherapy combined with deep inferior epigastric perforator (DIEP) flap and transverse rectus abdominis musculocutaneous (TRAM) free flap breast reconstructions post mastectomy for breast cancer**
REC reference:	**13/WM/0310**
IRAS project ID:	**100063**

The Proportionate Review Sub-committee of the NRES Committee West Midlands - The Black Country reviewed the above application on 26 July 2013.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator, Miss Shehnaz Ishaq, nrescommittee.westmidlands-blackcountry@nhs.net

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, **subject to the conditions specified below.**

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Other conditions specified by the REC

1. Please revise the Consent Form to include the following statement 'I understand that relevant data collected during the study, may be looked at by individuals from [company name], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.'

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You must notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Covering Letter		
Evidence of insurance or indemnity	[redacted]	01 August 2012
GP/Consultant Information Sheets	1	16 July 2013
Interview Schedules/Topic Guides	1	16 July 2013
Investigator CV	Miss Victoria Harmer	
Investigator CV	[redacted]	08 November 2012
Investigator CV		
Investigator CV		
Other: Letter from funder - The Breast Cancer Research Trust		11 October 2011
Other: Demographic Information	1	16 July 2013
Other: Email clarification re question A23 on application form		18 July 2013
Participant Consent Form	1	16 July 2013

Participant Information Sheet	1	16 July 2013
Protocol	1	16 July 2013
REC application	3.5	09 July 2013

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

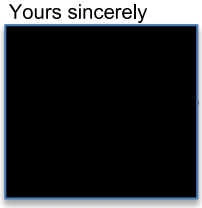
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
information is available at National Research Ethics Service website > After Review

13/WM/0310 **Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely



Email: nrescommittee.westmidlands-blackcountry@nhs.net

A Research Ethics Committee established by the Health Research Authority

Appendix 5: Consent form

Trust logo

P: 0203 xxx xxxx
E: Victoria.harmer@xxx

Consent Form

Women's Perspectives of Radiotherapy combined with Tissue-only Immediate Breast Reconstructions

Name of Researcher: Victoria Harmer

Name of Participant:

Patient Identification Number for this Study:

Date:

Applicants should tick the appropriate boxes and add their initials alongside

1. I confirm I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions of the researcher and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I agree to the interview/focus group being audio/video taped. ☐
4. I understand that information I provide will be published in a report and agree to the use of direct quotations in publications provided that anonymity is preserved. I give permission for these to be published. ☐
5. I understand that relevant sections of my data collected during the study, will be reviewed by Vickki Harmer and I give her permission to have access to my records. ☐
6. I agree that my general practitioner (GP) will be informed that I am taking part in this research. ☐
7. I agree to be contacted by Vickki Harmer by telephone one week after this focus group when I have the opportunity to inform her of any additional thoughts I have had on this subject. ☐
8. I understand that relevant data collected during the study, may be looked at by individuals from Kings College London, from regulatory authorities or from XXXX, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. ☐
9. I agree to take part in the above study.

Name of Participant	Date	Signature
Name of Person taking consent.	Date	Signature

When completed: 1 to be kept in research record, 1 for participant

Appendix 6: Demographic information

Trust logo

P: 0203 xxx xxx
E: Victoria.harmer@xxx

Women's Perspectives of Radiotherapy combined with Tissue-only Immediate Breast Reconstructions

DEMOGRAPHIC INFORMATION

Welcome to this focus group where we will discuss your thoughts about radiotherapy and your breast reconstruction.
Please can you fill in this form telling us a little about your background before we start the group.
Please hand this to Vickki when you have completed it.
This information is to help to describe our findings and those who participated in the study.

1. Your age in years – please tick

40–44	
45–49	
50–54	
55–59	
60–64	
65–69	
70–74	

2. Your ethnicity – please circle

White	• British • Irish • Any other White background
Asian or Asian British	• Indian • Bangladeshi • Pakistani • Other Asian background
Black or Black British	• Caribbean • African • Other Black background
Chinese or Other Ethnic Group	• Chinese • Any other ethnic group
Mixed	• White and Black Caribbean • White and Black African • White and Asian • Any other mixed background
Other	– please document

3. What type of breast reconstruction did you have?

TRAM	
DIEP	
Don't know	

4. How long ago did you have the reconstructive surgery?

_____

5. When did you complete your radiotherapy?

_____

6. Do you have any other non-cancer related health problems?

Yes	

Please detail	
No	

7. Your Occupation: _____

If you work are you:

Full-time	
Part-time	

8. What is your highest educational achievement/academic qualification?

_____

Thank you for completing this form. Please hand it to Vickki before we start the group.

Appendix 7: Search strategy and numbers of articles to identify appropriate qualitative systematic reviews

Found 3 from Medline, Embase and PsycInfo.
Ovid Technologies, Inc. Search for: 10 and 12 and 13 and 14 Results: 3

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present> Search Strategy:

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1 breast cancer.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (186074)
2 breast neoplasm*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (230564)
3 exp Breast Neoplasms/ (230649)
4 metasynthesis.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (149)
5 meta-synthesis.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (271)
6 qualitative research.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (27669)
7 qualitative research/ (22373)
8 systematic review.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (54760)
9 1 or 2 or 3 (272800)
10 limit 9 to (female and humans) (211536)
11 limit 10 to systematic reviews (4321)
12 4 or 5 (404)
13 6 or 7 (27669)
14 8 or 11 (58248)
15 10 and 12 and 13 and 14 (3)

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